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# Work-Life Experiences for People with Mobility Disabilities in New York City

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# Work-Life Experiences for People with Mobility Disabilities in New York City

by Jessica A. Murray

A master's thesis submitted to the Graduate Faculty in Liberal Studies in partial fulfillment of the requirements for the degree of Master of Arts, The City University of New York.

2014



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## Approval Page

This manuscript has been read and accepted for the Graduate Faculty in Liberal Studies in satisfaction of the requirement for the degree of Master of Arts.

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THE CITY UNIVERSITY OF NEW YORK

## **Abstract**

### WORK-LIFE EXPERIENCES FOR PEOPLE WITH MOBILITY DISABILITIES IN NEW YORK CITY

by

Jessica A. Murray

Adviser: John Seley, Ph.D.

Work-family (or work-life) studies aim to measure interactions between the realms of work and home. It is necessary to examine these interactions within a broad context to understand external sources of tension on the work-life dynamic, including environmental, economic, and political factors. Exploratory interviews were conducted with participants of working age with a mobility disability, and when applicable, their significant others. Questions focused on work, home and transportation environments. Using Bronfenbrenner's ecological systems theory, a model of contextual issues was constructed as the basis for an in-depth analysis of work-life issues for people with a mobility disability. Contextual research and insights from interviews were then examined using the person-process-context-time model: a theory of how individuals and environments change within the ecological systems framework. The findings reveal factors that uniquely impact quality of life and development for people with a mobility disability within the context of New York City. Questions for future research and policies are outlined.

## **Acknowledgments**

First and foremost, I would like to thank all of the people who participated in this research project, the interview participants, many of whom welcomed me into their homes and shared the intimate details of their lives. Even after becoming aware of mobility disability through a short-lived experience and researching various political issues, my understanding has evolved dramatically after having these conversations.

I would also like to thank my advisor, Professor John Seley, for opening my eyes to the importance of local context, and the potential for fostering social change through research. To Professor Colette Daiute, thank you for encouraging me to think more about development and change in relation to this topic.

And finally, thank you Gregor, for reading this paper in its entirety, for humoring my constant observations, and for caring enough to send interesting information about mobility my way. Your support in this project and in life have been invaluable.

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## **Chapter 1: Introduction**

Disability activists have worked tirelessly on inclusion for people with all types of disabilities, and this coalition has been important for advancing the rights of people with disabilities. Mobility disability is unique in the fact that there is a very specific type of environmental barrier that disable users of assistive devices who may otherwise have total access (Chinnery, 1990). For wheelchair users, a single step can be as insurmountable as a flight of stairs. These barriers also impact the partners or caretakers of people with mobility disabilities, and people at both ends of the lifespan, i.e., young children and seniors. Improving wheelchair accessibility would make life better for people with vision disabilities and for the nondisabled population who can, for example, roll their suitcases with ease over curb cuts mandated by the Americans with Disabilities Act. And yet, nearly 25 years after the ADA was signed into law, there are still many barriers to access in the built environment. The oft-touted cost burden keeps the status quo in a state of perpetuity, which is painfully obvious in places like New York City, where 19th century infrastructure represents a hostile environment to people with limited physical mobility.

### **Personal Motivations for Research**

Like millions of other people, I consider New York City to be my home. I moved here nearly six years ago, and plan to stay indefinitely. If I happened to be twice the age I am right now, I would have a 17.4% chance of having an ambulatory disability (Erickson, Lee, & Von Schrader, 2014). I'd likely stay close to home; after all, the bus takes a long time, and the subways are impossible. My interest in this topic is selfish. I can no longer experience the city without seeing barriers for people with ambulatory disabilities, a group that I know I will be part of eventually. With the best luck, it will happen when I'm much older, but I have an invisible

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disability, which will progress unpredictably. I experienced my first symptoms of multiple sclerosis in 2005 and was officially diagnosed in 2008. For most of the time since, I've managed well with disease modifying treatment.

I have experienced mobility disability twice while living here, and the incidents happened in close succession. In March of 2011, I severely sprained my ankle, and couldn't walk normally for about six weeks. Because I lived over half a mile away from the subway, I relied on taxis to get to work and back—an unexpected expense that I was fortunate to be able to handle financially. Shortly after recovering from the ankle injury, I had an MS relapse that affected my motor functions for the first time. The relapse may have been caused by a lack of physical activity after the sprain, or stress, or any other factor; the causes and triggers of MS symptoms are still unknown. The left side of my body became sluggish, and it was difficult to pick up my foot to walk. My hands felt arthritic, and my left hand was nearly unusable. When I had been incapacitated and unable to walk for weeks prior to the relapse, I could still type, use the mouse and do all the other things a graphic designer does. The loss of upper bodily function rendered me unable to work. I scheduled an emergency appointment with my neurologist and received a steroid IV. Both my upper and lower body motor functions were mostly normal within a few days, but it took two months for my symptoms to completely abate.

My coworker and supervisor reactions to both incidents were mixed, but they were generally supportive, thanks, in no small part, to the Family Medical Leave Act (FMLA) of 1993 which guaranteed that I could take an extended leave of absence in the event of an illness and return to the same job. If this had happened twenty years earlier, I could have faced losing my job and all of the benefits that came with it.

Both experiences opened my eyes to the reality of becoming disabled; the loss of

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movement was sudden and unexpected, and I quickly realized how much I relied on walking as a primary mode of transportation. The sudden increase in travel expenses was another abrupt change. I was fortunate that my injury and relapse weren't worse, but the cost of taxis to get to work was an unexpected blow to my finances. My experiences were still too short-lived to give me a sense of what people with permanent mobility disability live with on a daily basis. I've never had the experience of trying to navigate a wheelchair through a crowded sidewalk when there's only one curb cut on the corner, and it's going the wrong direction. I've never tried to go somewhere across town or to another borough by bus or Access-a-Ride. I haven't worried about building accessibility when scheduling a job interview or a doctor's appointment.

In the years since these experiences, I have become acutely aware of the places that are inaccessible to people with a mobility disability, and people with mobility disabilities have become much more visible to me. As a result, I've become more aware, and more critical of the state of accessibility in New York City. I see progress, but there are more barriers than smooth thresholds, more staircases than elevators, less progress than should be expected.

### **Importance of Mobility to Work-Life Studies**

Work-family studies have grown in the past two decades as researchers have identified benefits and conflicts between overlapping work and home domains. Theories of positive and negative spillover between domains have encouraged empirical research into variables that can create conflict between the two areas (Grzywacz & Marks 2000). The separation of home and work environments during the Industrial Revolution created geographical changes that have resulted in a temporal transition between the two locations (Hareven, 1976). There is little research in the work-family literature devoted to the transition between home and work domains, but recent sociological research has examined the impact of commuting on well-being (Olsson,

Gärling, Ettema, Friman, & Fujii 2013), and economic researchers are exploring the links between transportation, economic opportunity, housing and social mobility (Glaeser & Joshi-Ghani, 2014) The commute between home and work along with errands and social trips are often left out of work-family and psychology literature, despite the fact that daily travel is taking up more time each year (McKenzie & Rapino, 2011) and this travel can have a spillover effect on work and home environments (Novaco, Stokols, & Milanese, 1990). Urry (2007) suggests that the social sciences have turned towards understanding the myriad meanings and expressions of mobility, and recent research is looking at family mobilities in a broad sense, including daily mobility, residential mobility and migration (Holdsworth, 2013).

Because of the importance of transportation and mobility to the work-family concept, the additional time needed for traveling with a mobility disability is likely to impact the work-family interface in a unique way. In terms of social mobility and looking specifically at economic factors, adults with disabilities have disproportionately low earnings and low educational attainment in comparison with the general population (Profile America Facts for Features, 2012). The Americans with Disabilities Act (ADA) has been instrumental in addressing accessibility and providing protections against discrimination for workers with disabilities. But, since its passage, employment rates have actually decreased for people with work limitations (Nazarov & Lee, 2012), and many environmental barriers remain.

### **Separating Mobility Disability from the Umbrella of Disability**

Modern disability advocacy groups have based their efforts on building a coalition to gain political power. As a result, disability has become a homogenized word relating to any number of definitions. Contrary to applying the broad brushstroke of inclusion advocated by the modern disability rights movement, I wish to isolate the experience of mobility impairment in

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order to analyze the specific social and environmental barriers common for people with this type of disability. Socioeconomic impacts on the physically disabled are overdetermined by generalization, and by the history of social stigmatization, segregation and limited educational access for the disabled community as a whole. Additionally confounding are the range of mental, psychiatric, developmental and medical disabilities that coincide with mobility disability. For example, recent qualitative research was conducted in the state of New York to assess issues faced by the disabled population in different life areas, and included participants recruited through various advocacy groups (CQCAPD 2009). The results don't address issues specific to people with mobility disabilities, but offer a glimpse into the myriad problems faced by people with all types of disabilities. The results are overwhelming and seem insurmountable when faced as a whole.

Psychological research that focuses on mobility disability often deals with the experience of aging groups, since ambulatory difficulty increases dramatically with age. Recognizing that aging can skew other variables is a reason to research people of working age. Mobility disability research often revolves around isolation, decreased social engagement and depression. Many of these variables also correlate with aging, but there is evidence that mobility disability isn't as negatively correlated with quality of life as people often assume (Albrecht & Devlieger 1999). Unless someone has a personal experience or close relationship to someone with a mobility disability, their perception of disability may be based on brief encounters or stereotypes.

**Symbol of Disability.** Mobility disability stands out from the umbrella of disability because of its prevalence and visibility. Ben-Moshe and Powell, (2007) outline why the international symbol of accessibility (ISA) was originally created, and how it has come to symbolize not only accessible entrances and facilities, but also disability itself. They also outline

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other criticisms of the symbol, noting that people with mobility disabilities don't all use wheelchairs, but the literalism of the symbol excludes people with invisible disabilities who may face criticism for taking advantage of accessible parking spaces or other accommodations. They also highlight the symbol's focus on disability rather than the person or the type of assistance, like a ramped entrance that may also be useful to other people using wheeled carts or strollers. Other criticism of the symbol includes the relative passivity of the person in the wheelchair. Recent redesigns of the symbol that show a wheelchair user in motion are gaining traction (Figure 1), even being formally adopted as the official accessibility symbol by the New York State Senate this year (Chokshi, 2014).



*Figure 1.* Original International Symbol of Access designed by Susanne Koefoed in 1968 (left), and revised version created by Sara Hendren and Brian Glenney of the Accessible Icon project (right).

The struggle for rights and inclusion for people with mobility disabilities is different from other civil rights struggles because it involves a kind of environmental discrimination caused by inaccessible structures, most of which were built long before the ADA became law. This results

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in segregation of entrances, facilities and services into two groups: accessible and non-accessible. When universal design principles are successfully executed, the need for the ISA no longer exists, nor does the architectural segregation (Ben-Moshe & Powell, 2007). Still, the onus for accessibility falls squarely on the shoulders of people with mobility impairments, despite the fact that barriers to wheeled mobility impact many other groups.

**Paying to Ensure Rights for a Protected Class of Citizens.** Wheelchairs are often seen as a financial liability for businesses and public services. The costs associated with wheelchair accessibility are treated as burdensome, but there is evidence that the expense is often exaggerated, and that retrofitting buildings rather than planning for inclusive design leads to higher costs (Imrie & Hall, 2001, p. 20, 41). The cost debate distracts from the issue; as a society, we are building structures that actively discriminate, we have known about this discrimination for decades, and poor legislation and enforcement allows this practice to continue. The framing of accessibility as necessary only for people with physical disabilities, along with the litigious framework of the ADA appear to have caused further division and resistance to accommodating people with all levels of mobility. Framing universal access as a humane endeavor rather than a liability may be a way forward for the goals of the disability rights movement (Dunlap, 1997). We are far from a consensus that we should pay to ensure these rights, and that the cost is worth the benefit. As Ed Roberts and other disability rights advocates have said, “People with disabilities are the one minority that anyone can join at any time.”

**Causes of Mobility Disability.** The causes of mobility disability are numerous, including genetic disorders, obesity, progressive diseases, and injuries from war, violent crimes or accidents. There are also invisible causes of mobility disability that include asthma, heart disease and chronic pain. The causes of mobility disability affect each person differently, and

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functioning of the upper and lower body may be affected together or separately. The census, which has been collecting information on disabilities since the early 1990's has changed the categories of disabilities to fit with updated models of disability. Where *physical disabilities* originally encompassed all upper and lower body mobility impairments, new definitions in the 2008 American Community Survey (ACS) describe *ambulatory* and *self-care* disabilities as "difficulty walking or climbing stairs," and "difficulty bathing or dressing" ("United States Census Bureau History," n.d.).

**Defining and quantifying mobility disability.** There are criticisms of methods used by the census bureau, but it remains one of the few sources for demographic information about mobility disability. The census recently started collecting data on disabilities, and it has been modified various times since, resulting in reliability issues and an overall lack of consistent data for comparison purposes. Between the first long-form survey in 1990, and the following decennial census in 2000, the categories of disabilities changed substantially, and further modifications were made to the ACS in 2008. There is no data collected about assistive devices in either the long-form or short-form census.

**History of disability questions on the census.** The short form decennial census attempts to measure each household in the country, but only 1 in 6 households are asked to complete the long form, which has included questions about disability since the 1970's. The American Community Survey (ACS) was born of a necessity to reduce the cost and burden of using a long form survey tool for the decennial census, and will eventually replace the long form entirely. Every year, a sample of 3 million households completes the ACS. ("UCSF - Disability Statistics Center - U.S. Decennial Census / Supplementary Surveys / American Community Survey," n.d.). Measurement of the prevalence of disability is a recent addition to the census, including specific

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questions related to disabilities in the early 1990's. Further modifications were made throughout the decade, and the 1999 version of the ACS defined physical disability as “conditions that substantially limit one or more basic physical activities such as walking, climbing stairs, reaching, lifting, or carrying” (“United States Census Bureau History,” n.d.). Further modifications attempt to further distinguish different types of disabilities, with changes to the type of information collected as recently as 2008. The census now collects data for people with ambulatory difficulties, or “serious difficulty walking or climbing stairs.”

*Physical disability vs. ambulatory disability and self-care disability.* Changing the singular category of physical disability in the 1990 census to ambulatory and self-care disability in the 2000 census may have been intended to create a distinction between people with a lower body mobility disability, and people with both upper and lower body mobility, but because multiple selections are allowed, there is a high possibility of overlap not visible without access to the raw census data. At the same time, people with only upper body mobility disabilities may not know how to answer disability questions if they fall into neither category. Gaining access to census data may shed some light on these confounding issues, but without more specific census questions related to functionality and assistive devices, it may be difficult to find a true measure of prevalence, or to understand the range of severity of mobility disability.

***ADA definitions.*** The 1990 version of the ADA recognized walking and standing as major life activities, and was amended in 2008 to clarify the definition of disability in regards to the term *substantially limited*:

To have an ‘actual’ disability (or to have a ‘record of’ a disability) an individual must be (or have been) substantially limited in performing a major life activity as compared to most people in the general population.

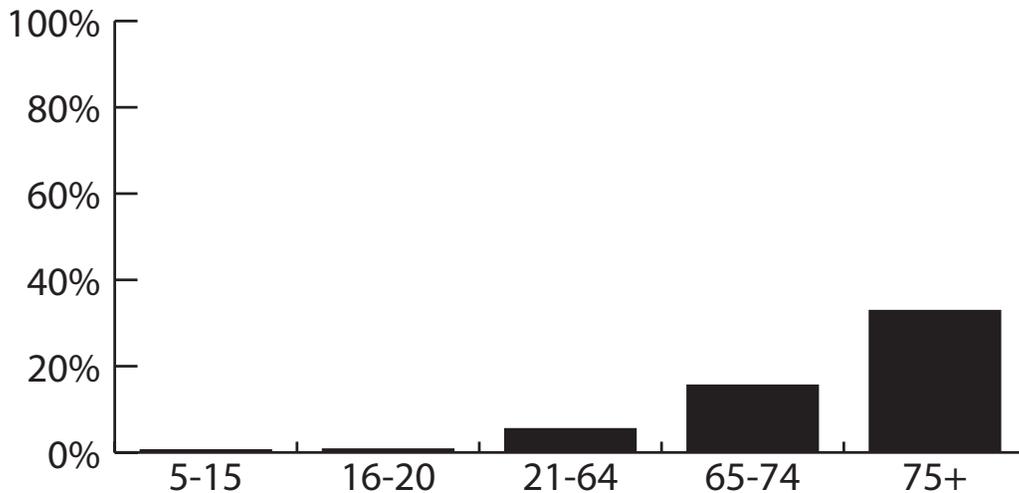
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The amendment does not require a particular length of time for a disability to be considered substantially limiting, and states “an impairment that is episodic or in remission is a disability if it would substantially limit a major life activity when active,” (ADA Amendments Act of 2008).

These two revisions expand the number of people with ambulatory disability to include individuals with temporary impairments, as well as those with diseases like multiple sclerosis, which can affect mobility during relapses. These are important distinctions that have the potential to greatly expand the number of disabled people, and by judging the number of EEOC complaints since the amendment, suggests that individuals with disabilities that were excluded in the ADA faced employment discrimination during that time (Annual Report on the Federal Work Force, 2011). Unfortunately, these numbers create more questions than answers, and more research is needed to understand the reasons behind employment disparity, and how it affects people with a mobility disability.

**Prevalence of Mobility Disability.** As a result of the definition change, there are only five years’ worth of data that show the prevalence of mobility disability in the United States. These numbers are also artificially low, as the disability questionnaire is only used to survey the non-institutionalized population (Brault, 2012). Still, we can see from data collected in the general population that the prevalence of ambulatory disability increases with age (Chart 1).

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*Figure 2.* Prevalence of ambulatory disability. The percentage of non-institutionalized, male or female, all races, regardless of ethnicity, with all education levels in the United States who reported an ambulatory disability in 2012. (Erickson, Lee, & Von Schrader, 2014)

***National and Local Demographics.*** National surveys on the use of assistive devices show a dramatic increase in use from 2000 to 2010. The number of wheelchair or scooter users has more than doubled in ten years, from 1.7 million to 3.6 million (1.5%), and users of other mobility devices, like canes, crutches, and walkers has grown from 6.1 million to 11.6 million (4.8%), (Brault, 2012).

2012 census data reports more than 500,000 people with serious difficulty walking or climbing stairs living in the city, under half of which are working age (226,892 CI=90%, [217,985, 237,799]). Less than a third of those with ambulatory disabilities are currently participating in the workforce; employed (54,692 CI=90% [52,203, 57,181]), and unemployed (14,450 CI=90% [13,388, 15,512]). According to the 2010 ACS, the percentage of New York City's population over the age of five with ambulatory difficulties is 6.5%, or nearly 500,000 people (U.S. Census Bureau, 2010, *New York City, NY-Sex by Age by Ambulatory Difficulty*).

Based on the small amount of data that has been collected through the ACS since the

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most recent definition change, there is a trend showing that the population of working New Yorkers with ambulatory disabilities has decreased, (-6,533, CI=90%, [-11,491, 1,575]) in the population aged 18-64 reporting ambulatory disabilities from 2008-2012, while the overall population for the same age group increased (108,299, CI=90%, [102,022, 114,576]). (U.S. Census Bureau, 2012, *New York-Employment Status by Disability Status*).

While four years of data may be insufficient to establish a long-term trend, and it is likely that economic factors have a greater impact on this particular group, the numbers still raise the question of why the disabled working population's ranks are decreasing while disability is increasing nationally. How do people with physical disabilities living in New York City make sense of the dominant representations and perceptions of disability, their minority status, and the current state of their opportunities and environments?

### **Exploratory Interviews and Pilot Study**

As part exploratory and part pilot study, I created a set of questions to find out how having a mobility disability impacts work, transportation and personal life spaces. A purposive sample was created at the outset to seek out working adults with an ambulatory disability as defined by the census. Categories were created to capture a range of experiences within this population, including people with and without children, spouses or significant others, and people with differing severities of disability. I also sought out activists involved in the disability community that might have greater insights into common experiences. The target sample consisted of 14-17 people: 1-2 male and 1-2 female activists, 2 single males and 2 single females without children, 1 female and 1 male with a disability living with a significant other (no children at home), and their nondisabled partners, 1 female and 1 male with a disability living with a significant other (with children at home), and their nondisabled partners, and 1 female and

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1 male single parent. For the purposes of obtaining permission from an independent review board, I doubled the number of participants in each category in case there were duplicates. Only one category—female, married or cohabiting, non-parent—had two participants. I originally sought to interview only labor force participants with an ambulatory disability, but quickly discovered the challenges in finding this sample in a population with a 25% workforce participation rate, and modified this criteria.

In addition to relaxing my workforce participation criteria, I also decided to offer an incentive for participation; a \$40 payment. After considering the time and economic constraints of the population I was seeking access to, this incentive proved to be a crucial tool for recruiting efforts, and the majority of participants agreed to be interviewed after this change.

**Participants.** I was able to fulfill more than half of my purposive sample, and interviewed a total of ten people in a variety of work and family situations (see Table 1). The participants missing from the sample were parents and people who were married or cohabiting. I was unable to find any women with disabilities who had children, and interviewed only two men with disabilities who had children under the age of 18. Participants included a people with a combination of upper and lower body mobility limitations. Half of the participants had personal care assistants, three of which were full-time, meaning they required multiple assistants (in these cases, 4 or more). The other two had part time assistants with their significant others or coworkers helping them with basic daily care needs the rest of the time.

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ID	Marital Status	Gender	Upper Body Functionality	# of Children at Home	# of Children	Children's Ages (by age range)	Employment Status	Informal Labor?	Personal Care Attendant?	Partner Caretaking Role?
1	M	M	L	1	1	1	SELF	N	FULL	-
2	M	F	-	1	1	1	FULL	N	-	Y
3	S/D	M	H	2	-	2	PART	N	-	-
4	S/D	M	H	3	-	3	SELF	N	-	-
5	L w/ S.O.	M	M	-	-	-	UN	Y	FULL	-
6	L w/ S.O.	F	H	-	-	-	UN	N	PART	-
7	L w/ S.O.	M	-	3	-	3	RET	N	-	Y
8	M	F	L	-	-	-	FULL	N	PART	-
9	S	F	H	-	-	-	PART	N	-	-
10	S	F	M	-	-	-	UN	Y	FULL	-

*Table 1.* Participant Profiles. Values for marital status; M=Married, S/D= Single/Divorced, L w/ S.O.= Living with Significant Other, S=Single. Values for upper body functionality; L=Low, M=Medium, H=High. Value ranges for children’s ages; 1:0-5, 2:6-18, 3:19+

Of the ten participants, only two requested anonymity, and in the interest of one partner who requested anonymity, her significant other was also given a pseudonym. Because of the nature of the snowball sampling, most of the people I interviewed knew, or knew of the other participants through affiliations with support groups and disability community. Because of the tightly knit and interwoven connections of my sample, I decided to assign pseudonyms to everyone in the group, despite their willingness to share their first or full names. After completing a draft, I sent the paper to participants who waived anonymity, to give them the opportunity to see how they were portrayed and consent again to use their name. In the end, six of the participants chose to use their identities.

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**Settings.** The majority of interviews took place inside participants' homes. Only two interviews took place in other settings, one in an office of a participant's workplace, and the other at a coffee shop. Interviewing people at home had several benefits, including convenience for the participants and the ability to observe and ask questions about their immediate surroundings. In traveling to the homes of the participants, I was also able to observe the accessibility of the subway and the state of sidewalks and curb cuts on the way to their apartments. Half of the participants lived in Manhattan, and four were in Brooklyn, Queens, and the Bronx. One participant lived outside of the city but had previously lived in Manhattan, and commuted regularly for work.

**Questions and Application of Answers.** The interviews were all semi-structured and lasted from 60-90 minutes. In cases where activists were interviewed, there were questions related to their particular area of interest or expertise, including housing, transportation, employment or education. Other questions varied according to the amount of time available, and the individual work and family situations. A list of questions was compiled and structured around three areas; work, home and family, and transportation. Many of these questions concerned environmental aspects of these three areas, as well as conceptual supports such as manager support, personal care, and family support. Several questions also addressed how long participants had lived in New York City, where their extended families lived, their plans for the future, and advice for people experiencing disablement.

Because the individual family and work situations of the participants varied, some questions were irrelevant, or focused on past experiences. For example, one partner of a woman with a lower body mobility disability was recently retired, but could recall the increase in domestic responsibilities and pressures from an unsupportive manager after his partner became

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disabled. In the case of unemployed participants, questions related to work environments were not relevant, and questions related to transportation applied to situations other than commuting, such as physical therapy, doctors' appointments and support group meetings.

**Additional Data Sources.** Several online data sources offer a glimpse into the local disability community, as well as individual experiences with mobility disability. A number of people have used film as a medium to illustrate the difficulties of getting around in a wheelchair. One filmmaker, Jason DaSilva (a participant in this study) has chronicled the decline of his motor functions after being diagnosed with primary progressive multiple sclerosis in a feature length film, *When I Walk*. A shorter feature for the New York Times highlights his limited transportation options once his mobility limitations require him to use a scooter (DaSilva, 2013). There are a number of videos on *YouTube* dedicated to various obstacles in New York City including missing curb cuts and poor sidewalk quality.

Comments and posts on social media by local advocacy groups also serve as a good source of pertinent issues. Blogs like [www.badcripple.blogspot.com/](http://www.badcripple.blogspot.com/) dedicated to life with a mobility disability are another source for experiences that illuminate social and environmental barriers. Excerpts from these online sources will also serve to highlight experiences of people with mobility disabilities living in the New York metropolitan area. Keeping context in mind was important for understanding the experiences of the people I interviewed. Local news sources serve to provide some of this context in later chapters.

### **A Note on Language**

There have been many disagreements within the disability community on the language to use when referring to disability and impairment. Terms like handicapped and wheelchair-bound have been rejected because of what they imply about the abilities and liberty of the individual.

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While the words disability and disabled imply an absence of ability, the community has accepted, if not embraced the term, and according to the social model, can support the conclusion that disability is a direct result of how society has been built. Rather than using the contrary abled or able-bodied, I will distinguish those without disabilities as nondisabled as Linton (1998) suggests. Additionally, I will refer to caregiving only when it refers to care by a family member. Home care aides, health care aides, and personal care attendants will be referred to as personal assistants. In some cases, participants used the words wheeling or rolling, but most also used walking to describe traveling by wheelchair, so I'll do the same.

## **Chapter 2: Literature Review**

In formulating my research questions, I drew from two areas in psychology and liberal studies to find relevant topics for interview questions and analysis: work-family studies and disability studies. Other than stresses caused by a caretaking role in addition to roles within the family and workplace, there is little research on mobility disability within the work-family literature. Similarly, there are few work-family perspectives in disability studies beyond critiquing social and political issues that limit work opportunities, and discussions about rights of disabled parents or experiences of parents of disabled children.

### **Work-Family Studies**

Work-family studies can be described as a cross-disciplinary set of inquiries into the modern life spaces of individuals and families, with a focus on work and family or personal life, and the interactions between the two areas. The basis for studying the work-family dynamic is rooted in organizational psychology and built on a desire of business leaders to limit distractions coming from external sources. Some corporations focused on developing childcare programs in the 1970s and 80s to accommodate women entering the workforce. Others developed Employee Assistance Programs (EAPs) that identified links between stress, depression and illness, and decreased productivity (Harrington, 2007). As many have discovered in modern workplaces, the bottom line can be affected by ensuring that workers are satisfied at home and in their personal lives. Today, there are many disciplines involved in studying this area, which is part of the reason work-family literature is so loosely defined (Barnett, 1998). Economists, psychologists, sociologists, organizational behaviorists, and management professionals are all interested in understanding how work—which consumes roughly a third of a full-time worker's time—interacts with personal lives. As communication technology has improved and taken a more

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prominent role in modern life, the boundaries of work and home continue to blur more, calling greater attention to the possibility for conflict, and a need to work towards work-life fit.

**Work-Family vs. Work-Life.** One area of debate within the literature is the naming of the field as work-family studies. While there is plenty of empirical research involving family make-up and possible conflicts between family and work responsibilities, many argue that naming the field work-family excludes single people, and negates the complexity of personal lives outside of the family. There are some that argue the field should be called *work-life studies*, as it is more commonly referred to in popular media, and because of recent attention given to work-life balance (Lewis & Dyer, 2002). Barnett (1998) also argues that the field should be called *work/non-work studies* to express the notion that the two areas are roughly similar in the amount of time they take up, and in importance to the individual.

Moving past semantic disagreements to encompass life beyond family requires looking at the many areas that make up a person's life experience. Life space is described as the totality of possible events that make up a person's existence, including environmental, social and psychological aspects of different spheres of life (Lewin, 1936). Lewin's concept of life space, or field theory recognized that people and events don't occur in isolation, and was conceptualized to observe the influences of intangible forces, paving the way for theoretical models that could better explain these complex interactions.

**Major Theories of Work-Family Studies.** Since the time of Lewin's life space and field theories, organizational psychologists have moved away from the complexity of life spaces to identify and empirically research direct ties between family and work roles. Relevant theories in the work-family psychology literature are outlined below.

***Work-family conflict theory and & work-family enrichment theories.*** Work-family studies have focused on negative aspects of the work-family interface: spillover and conflict in both directions, i.e. work to family conflict or family to work conflict (Voydanoff, 1988). More recently, greater attention has been given to positive spillover, or work-family enrichment, which assumes positive benefits of both being employed and having a family (Greenhaus & Powell, 2006). The root causes for negative vs. positive spillover can range from concrete circumstances, such as economic resources, to more abstract concepts, such as supervisor support at work, or an equitable distribution of labor at home. These competing theories make up a substantial portion of the literature, and help to explain other subtopics within work-family psychology.

***Work quality, autonomy, flexibility and supervisor support.*** Subjective experiences of work act as buffers to work family conflict, and include quality of work, personal autonomy and control over job functions, control over time and place of work, and perceptions of supervisor support. Typically, jobs that provide all of these qualities are also considered to be a meaningful part of a career, and empirical research often focuses on the kinds of white-collar jobs that allow for autonomy and flexibility of work schedules.

***Role theory, division of labor, and economics of the home.*** One of the earliest theories in the work-family literature is role theory; the work and family roles taken on by men and women and how these roles function as a system (Pleck, 1977). Traditional gender roles and paid and unpaid labor factor into this system. Given the assumption of a household having one or two earners, and the need to distribute or outsource unpaid domestic labor, a negotiation occurs between couples to equitably distribute responsibilities. Research finds that women are typically responsible for the majority of domestic work (Bianchi, Sayer, Milkie, & Robinson, 2012), and in many cases, they use their paid labor earnings to offset their domestic responsibilities (Treas

& Ruijter, 2008). Rather than the male partner taking on a greater share of domestic responsibilities, women tend to use their economic resources to pay for outside help, whether it's childcare or other domestic work like cooking and cleaning.

***Psychology of unemployment.*** Based on the concepts of role theory, division of labor, and work-family enrichment, the next logical step in assessing work-life quality is to examine the psychological effect of the absence of work. While the topic of unemployment and mental health is covered extensively in management and vocational behavior research (Paul & Moser, 2009), the work-family literature often covers women's unemployment in relation to her partner's status in dual-earner households (Chesley, 2011). There is an awareness of the need for research in this important area, given the changes in the global economy in the last decade (Kalil, 2009). Other recent analysis of research has focused on differences between psychological health for employed and unemployed individuals. While some of the studies controlled for marital status, other economic aspects of the work-family relationship, such as breadwinner status of the unemployed individuals were not explored (Wanberg, 2012).

I was unable to find any studies about unemployment due to mobility disability in relation to work-family issues. One study examined the impact of physical disability and unemployment on mental health (Turner & Turner, 2004), but didn't include information about the participants' family make-up. Given the current low employment rates for people with disabilities, the impact of unemployment deserves greater attention.

***Criticisms of work-family literature.*** In addition to the need to better define the work-family concept, and incorporate complex external factors into the analysis of work-family conflict and enrichment (Barnett, 1998), there are also criticisms of whom the work-family literature addresses. The term family is taking on new meanings in recent times, and traditional

gender roles and family compositions are shifting at the same time.

***Heteronormative bias.*** Research into work to family conflicts for fathers is a very recent phenomenon, as dual-earner households and households with breadwinning mothers and stay-at-home fathers are on the rise (Kramer, Kelly, & McCulloch, 2013). Given that families no longer fit into the neat, nuclear packages of mother, father and 2.3 children, it is surprising how little work-family research focuses on GLBTQ relationships or blended families. Perhaps the field simply hasn't caught up, or more recent developments into the understanding of diversity within the gay community have proven challenging (Demo & Allen, 1996).

***White-collar bias.*** Similarly, a dearth of research exists for work-family situations outside of couples where one or more member is employed in a white-collar industry. Topics of inquiry including flexible work schedules, telecommuting, and job autonomy don't typically apply to people working in blue collar or service industry occupations. There is potential for many areas of research that affect low income workers, including the lack of flexibility in scheduling, the possibility of juggling more than one job, inability to secure health insurance, or the financial strains of supporting a family on one income. As these topics gain more mainstream attention, and given the recent fight for an increase in the minimum wage in the U.S., it is clear that the work-family literature will likely follow suit.

***U.S. and western-centric research.*** While the bulk of work-family studies have been conducted in the U.S, recent work-family research has expanded beyond the western world to examine cultural differences in attitudes towards work-family concepts. Interestingly, compared to western countries, China and Latin American and countries report less work-family conflict (Spector et al., 2004), while some countries with more generous social supports actually report higher levels of work-family conflict (Allen et al., 2014). The cultural dimension frames the

unique context of place and heritage around work-family issues.

**Mobility Disability in the Context of Work-Family Studies.** Just as there is little research exploring work-family topics for non-nuclear families, low-income groups, and non-western cultures (Parasuraman & Greenhaus 2002), there is a lack of research about the working lives of people with mobility disabilities. Current research on disabilities and work-family issues look at family-to-work conflict for people with a caregiving role, and applies to caring for a family member with any type of disability (Marks 1998; Lewis, Kagan & Heaton 2000). There is research on how spinal cord injuries impact a person's desire to return to work (Ville & Winance 2006), but none examining the intersection of mobility disability and work-life issues, especially when a parent or spouse has a mobility disability.

There are some studies that examine the quality of life, or life satisfaction among those reporting severe disability. Positive correlations exist between life satisfaction and employment, income, education, job satisfaction, leisure activities, and social integration (Mehnert, Krauss, Nadler, & Boyd, 1990). Studies related to unemployment also show a negative correlation between quality of life, financial strain and unemployment (Ervasti, & Venetoklis, 2010). A recent national survey of the disabled found a gap of 27 percentage points in those with disabilities saying they are very satisfied with life in general than those without disabilities (34% versus 61%, respectively). Of the group surveyed, 73% of unemployed were unable to work due to their disability or health problem, 42% thought they couldn't get the accommodations needed to perform their job and 32% worried that the income would make them ineligible for federal health benefits (Kessler Foundation/National Organization on Disability, 2010).

Many of the prevailing concepts in the work-family literature examine the ways that people adapt to their individual situations and how factors in the home microsystem have an

influence on the work microsystem. Topics like work-family enrichment, role theory, and job autonomy and flexibility may have different dimensions for people with mobility disabilities.

### **Disability Studies**

Disability studies is a fairly new (mid 1990s) academic discipline in the liberal arts that focuses on the experience of having a disability, and what it means to be disabled in the world, now and throughout history. The disability rights movement has initiated theories and models of disability and challenges to the language, definitions and symbols created by our culture. Other topics of interest include portrayals of disability the media, stigmatization, gender, and identity.

**A brief history of the disability rights movement.** It would be impossible to detail the entire history of the disability rights movement in this paper, but it is important to understand how this context has shaped the attitudes of people living with disabilities. During an interview, one of the participants summed up this history very succinctly:

George: Beginning stages, we were killed, later on we were institutionalized, and now, finally, on some levels, folks are fighting and they're being heard, and so government and society's being forced to include us in things. All over again. But it's not—our voices are not loud enough, or strong enough.

This complex history is important context in terms of federal and local policies and the current state of disability rights. By interviewing people who are experiencing mobility disability at this point in time, I hope to connect those voices in a way that might promote new ways to think about inclusion and urban mobility.

***Institutional and charitable approaches.*** The first aid to people with disabilities in the U.S. appeared in Boston in the mid-19th century in the form of a school for children with disabilities, organized by Samuel Howe. What began as a temporary home to teach children with

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various disabilities practical knowledge before they returned home, became the permanent institutionalization of people who were assumed to have no valuable skills to offer society, or possibility of caring for themselves. The policy of institutionalizing people with a variety of “defects” continued for over a century, coinciding with the eugenics movement, which resulted in sterilization laws in 33 states (Pfeiffer, 1993). Simi Linton further describes the treatment of people with disabilities as pariahs in *Claiming Disability*:

Many disabled people around the globe have stories to tell of abuse and marginalization. [C]asting out and vilifying disabled people is the extreme end of a long and complex continuum, (1998, p. 45).

Shapiro (1993) describes the turn to a charitable movement for disability rights after WWII, with the support of parents of people with disabilities who were frustrated by the lack of social and medical support. Individual charities were created to assist people with various physical disabilities, including muscular dystrophy, or cystic fibrosis (p. 78). The groups also funded lobbyists to have a permanent presence in Washington, and began developing a special curriculum for students with these conditions. While their support was intended to keep their children out of institutions, the special curriculum created the segregation of disabled children in schools, a trend that advocates are now trying to reverse.

***The Independent Living Movement.*** The Independent Living Movement grew out of a desire for people with disabilities to come out of the institutions and become part of the communities they lived in. For people with mobility disabilities, this meant that the physical environment had to be altered in order to achieve their independence. Activist Ed Roberts founded the first *Center for Independent Living* in Berkeley, CA in 1972. He contracted polio as a teenager and was the first student with severe disabilities to attend UC Berkeley. The city went

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on to recognize the importance of mobility to independence, embracing the push for accessibility for wheelchairs in the early 1970's, and creating curb cuts throughout the city.

*A coalition for civil rights, and the Americans with Disabilities Act.* Much of the activism for independent living and disability rights coincided with the civil rights movement in the 1950s and 60s. There were many parallels that could be drawn between segregation and discrimination for minority races and people with disabilities, but it took decades for advocacy groups and people with different types of disabilities to see their plight as a matter of human rights, and push for policy intervention at the federal level. The passage of Section 504 of the Rehabilitation Act of 1973 helped to galvanize the idea of civil rights as the first mandate passed into law. The brief text of the section included the first mention of disability and discrimination:

No otherwise qualified individual with a disability in the United States, as defined in section 705(20) of this title, shall, solely by reason of her or his disability, be excluded from the participation in, be denied the benefits of, or be subjected to discrimination under any program or activity receiving Federal financial assistance...

Fifteen years later, the ADA was introduced to congress. In 1990, a major protest in Washington D.C. dubbed the Capitol Crawl, brought national visibility to the material discrimination faced by people with mobility disabilities, as they left their wheelchairs and crawled up dozens of steps of the capitol building. This symbolic gesture brought awareness to the most overwhelming barrier for people with mobility disabilities; the man-made environment. The ADA was signed into law two years later.

**Major models of disability.** While there are many ways to look at disability within a wide cultural context, there are two major competing models for philosophical discussion within

disability studies. The medical model is based on a treating an individual's disability as an illness. When no cure exists, the disabled person is treated as handicapped or impaired. The social model—which is a reaction to and rejection of—the medical model, asserts that society disables individuals who should have the chance to participate more fully in society. This disablement occurs through barriers in the built environment, paternalistic government policies, and societal attitudes that treat people with disabilities as less capable than those without disabilities.

***Medical model.*** The medical model of disability has historical roots going back to the early days of medicine and the scientific method. In this model, the individual's condition was treated as a problem to be fixed, with no thought given to social barriers, or supports that may be lacking. In this approach, people with disabilities are seen to be defective. Often, an impairment would translate to incompetence in other areas (Linton, 1998, p. 25)

*World Health Organization definitions.* The medical model of disability was validated by the WHO, which attempted to standardize the definition of disability in 1980. Original characterizations included *impairment*, *disability* and *handicap*, describing *abnormalities*, *limitations*, and inability to perform *normal* human functions.

***Problems with the medical model.*** Despite the well-meaning intentions of the medical community, there is a lack of holistic care that may be impacting quality of life for people with disabilities. The main criticisms of the medical model are the expectations placed on the disabled person to adapt, or the often-impossible hope that therapy, rehabilitation or assistive devices can return them to normalcy. Because of the complexity of insurance and care in the United States, the cost of care for individuals with severe physical disabilities is very high.

*Looking for a cure.* The medical model of disability has a long history, and despite recent attention given to the social model, society has not entirely moved away from a medical

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approach to disability. The hope for new scientific breakthroughs like Jonas Salk's discovery of an effective polio vaccination often dominates discussions about chronic disease. Research into cures for chronic illnesses remain the top priority of most disease-focused organizations, while supporting people with these illnesses is a secondary mission. Disabled authors and activists advise transitioning individuals who are newly injured or diagnosed not to hold out hope, but to accept their new circumstances and find a way to live a fulfilling life (Karp, 1999). There is continued development of assistive devices, like exoskeletons, with the noble goal of helping patients walk again. However, little thought is given to the cost and availability of these alternatives, and for some, exoskeletons are an impractical alternative to a using a wheelchair because they don't completely restore the ability to walk, but rather provide assistance in standing and traveling short distances (Peace, 2013).

*Disparity of health care access for PWD.* The medical industry seems to be failing to help people with mobility disabilities maintain their overall health. A recent study sought to make appointments for fictional obese patients at subspecialty practices in four cities and found that more than 20% could not accommodate the patients, for reasons such as inaccessibility of the building or inability to transfer a patient to an examination table (Lagu et al., 2013). Chen (2013) examines this study and others to find the root of the disparities, citing lack of funding for accessible equipment, reimbursement for extra time needed to care for patients with physical disabilities, and lack of clear guidelines for health care facilities in the ADA. Discrimination by medical doctors of people who are overweight or obese can also lead to avoidance of preventative care (Sabin, Marini, & Nosek, 2012).

*Preventing disablement falls outside the medical realm.* In addition to the inability of the medical industry to cure or care for people with physical disabilities, prevention falls outside the

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realm of healthcare. Injuries from car accidents, gunshot wounds, or war injuries are social problems that are difficult to address on their own. Similarly, genetic determinants of mobility disability cannot be prevented. Regardless of the cause of disability, the medical model can't possibly address the needs of everyone who becomes disabled.

*Environmental and structural issues.* The most important criticism of the medical model is that it fails to address the environmental barriers that make adaptation difficult. While mobility devices have come from the medical realm as a solution to improve independence for people with mobility disabilities, the changes needed to ensure actual independence also fall outside the medical realm. In some cases, manual wheelchair users can be lifted over small barriers, but because of the weight of power chairs, their users are unable to adapt even with the help of nondisabled people. Environmental changes needed to ensure that the use of mobility devices is unhampered are slow to materialize, possibly because of the many regulations for accessibility in construction of new buildings and for alterations (Guidance on the 2010 ADA Standards for Accessible Design, 2010). These guidelines coincide with larger structural issues; policies and budgets fail to prioritize the needs of wheelchair users.

*Social model.* The social model of disability asserts that disability is a systemic, societal oppression of people who fall outside of physical norms (Hutchison 1995). The social model points to environmental obstacles as the true cause of disablement, especially for people with physical disabilities. Remarkably, the recent prominence of the social model of disability has influenced the World Health Organization's definition of disability to change from focusing only on individual impairments to acknowledging external factors that cause disability:

Disability is thus not just a health problem. It is a complex phenomenon, reflecting the interaction between features of a person's body and features of the

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society in which he or she lives. Overcoming the difficulties faced by people with disabilities requires interventions to remove environmental and social barriers ("Disabilities," n.d.).

*Rights vs. pity or charity.* One of the main struggles of the disability rights movement is that the needs of people with disabilities have historically been met by charitable organizations. Sometimes called the charity model of disability, this solution to fixing social problems is often seen as another paternalistic way to deal with issues that should be treated as civil rights (Samaha, 2007). Some argue that charities aligned with helping the disabled lead to casting a pitiable image on a diverse group, and further discrimination as a result (Shapiro, 1993, p. 65).

*Discrimination, stigma, exclusion, and isolation.* Much of the stigmatization and discrimination stems from pervasive social attitudes that people with disabilities are victims of a biological impairment, in need of help and social support (Fine & Asch, 1988). Activists argue that attitudinal barriers are proliferated by discrimination based on deeply ingrained attitudes towards people who are seen as abnormal. These barriers, fueled by media portrayals of people with physical disabilities as monstrous, embittered or angry (Nagler, 1990) lead to decreased socialization and increased exclusion and isolation of people with disabilities (Heatherton, 2003).

*Problems with the social model.* Despite the momentum of the social model of disability in the past few decades, there are still some areas that the social model fails to address, namely prescriptive measures to address the social issues that stubbornly oppose progress (Samaha 2007).

*Passing the buck on accessibility.* In the wake of the passage of the ADA, there was uproar among business owners about the unfunded mandate to create accommodations for people with disabilities. Lacking an enforcement mechanism, the true progress of accessibility improvements has varied by location and government structures. For example, in New York City,

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the responsibility of sidewalk accessibility is left to individual property owners and loosely enforced by the Department of Transportation, and transportation accessibility is left up to the Metropolitan Transportation Authority (MTA), a quasi-governmental organization described as “A public benefit corporation chartered by the State of New York” (“MTA” n.d.). Even the city government, which arguably has a large stake in its public transit network, has little say in its operations or budget decisions.

*Deserving and undeserving groups.* There are similarly no prescriptive social solutions to address the continued stigmatization of disabled people. The current political debate surrounding entitlement reform threatens the financial stability of people with disabilities and further marginalizes them within society. For people with physical disabilities, there is somewhat of a hierarchy of deservingness that accompanies much of the discussion. Similar to general welfare recipients, there are a certain set of criteria imagined by the public that may serve to filter people receiving disability benefits into two categories (Jeene, Oorschot, & Uunk, 2013). People born with disabling conditions, or the elderly may be deserving of social support while a gunshot wound victim or someone with severe obesity may be seen to have had a hand in determining their own circumstances, and therefore undeserving of help.

*Resisting medical advances and adaptive technology.* Another criticism of the social model is its rejection of efforts to fix impairment; despite the potential for advances in drugs, therapies and adaptive technology to improve quality of life. For people with progressive physical disabilities, there is a reluctance to progress from canes or walkers to a wheelchair or scooter (Finlayson & Denend, 2003). Some of this may be a matter of poor fit or limited user input; in a study of assistive device abandonment, nearly 30% of devices were abandoned within five years (Phillips & Zhao, 1993). There is also evidence that stigma is attached to the

perception of assistive devices (Parette & Scherer, 2004), which may influence willingness of people with disabilities to adopt novel assistive devices.

### **Methods and Theories**

In setting out to understand the experience of living with a mobility disability in a location-specific context, I am acknowledging the complexity of the phenomenon while examining structural issues rather than attempting to reduce individual experiences to a single shared experience. Seeing the individual situated within their family, work and social situations, as well as branching out into the larger context of their community, New York City, and beyond guides this approach. The methodologies and theories outlined below are not intended to produce empirical knowledge, but to guide exploratory research as a first step for further research.

**Methodologies.** For the purposes of conducting an exploratory study, several methodologies helped guide this initial phase of research. The following study was conducted with three methods in mind; phenomenology and descriptive research.

**Phenomenology.** In brief, phenomenology is the study of lived experience. In its earliest form, pioneered by 20th century philosopher Edmund Husserl, phenomenology was largely concerned with describing the *essence* of shared experience and consciousness by reducing experiences as much as possible. Another philosopher, Martin Heidegger took an interpretive approach to phenomenology, developing the concept of hermeneutics—a branch of knowledge concerned with interpreting biblical texts—into a way to interpret consciousness in the context of a person’s surroundings. In the 1970s, Amedeo Giorgi adapted the philosophy into a descriptive phenomenological method, which shaped qualitative research as a scientific approach to understanding subjective data.

The two main approaches to phenomenology in psychology are descriptive and

interpretive methods, but interpretations and uses of phenomenological methods vary greatly (Schmicking & Gallagher, 2009). Under a descriptive approach, the researcher attempts to assign meaning to the experiences of a group of individuals who share a certain phenomenon, in this case, living with a mobility disability in the context of a specific city. Rather than trying to find a causal connection, phenomenological research produces a description of how the shared phenomenon affects individuals, and then categorizes these experiences. There is necessarily some interpretation involved in the process, and there are variations of methods employed in phenomenological research. For the purposes of this study, I am using participants' descriptions as a way to illuminate various facets of their experience. While some researchers attempt to eschew theoretical underpinnings and enter the research without prior knowledge of the phenomenon, I have taken the approach of utilizing an existing theoretical framework to establish the bounds of the phenomenon I am studying, and have filled in relevant context based on research, interviews and conversations.

***Descriptive research.*** The term descriptive research is also broad and encompasses several other methods including observation, case studies and surveys. Like phenomenology, descriptive research is not concerned with finding causal connections, but simply paints a picture of experiences or attitudes of a population. Demonstrating shared experiences within a well-defined population can illuminate specific problems, and allows for the possibility of longitudinal studies that can show changes within the group over time. Understanding the experiences of the population of interest may benefit policy makers and advocates who are working to improve quality of life for this group; in this case, in a local context.

**Ecological Systems Theory.** Ecological systems theory (Bronfenbrenner 1989) is an exploratory framework that allows for the study of life domains as distinct but interconnected

and embedded systems. Similar to the life space concept developed by Lewin, Bronfenbrenner organizes the complexity of different life areas, describing five different systems; micro, meso, exo, macro, and chrono. Starting at the smallest level, microsystems are the immediate environments or people surrounding the individual; home, school, work, family, and social circles. The mesosystem describes the interactions between microsystems, which would include relevant work-family theories such as work-family conflict and enrichment. The exosystem consists of the macrosystems of other people close to the individual, and environments that the individual is sometimes a part of, but they will make up a small part of their experience. The macrosystem and chronosystem consist of external environments that also have an impact on the individual's life, including local businesses, doctors, communities and transit networks. These external systems also contain more abstract environments that affect development, including government policies, societal attitudes, and historical events.

***The Person-Process-Context-Time Model.*** The purpose of ecological systems theory is to understand the role of the environment on development of the individual, along with the interaction between different ecosystems. Further development of this theory includes the Process-Person-Context-Time (PPCT) Model (Bronfenbrenner, & Morris 2006), which aims to better understand the process of change for the individual within a specific historical context:

The first of these, which constitutes the core of the model, is *Process*. More specifically, this construct encompasses particular forms of interaction between organism and environment, called *proximal processes*, that operate over time and are posited as the primary mechanisms producing human development. However, the power of such processes to influence development is presumed, and shown, to vary substantially as a function of the

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characteristics of the developing *Person*, of the immediate and more remote environmental *Contexts*, and the *Time* periods, in which the proximal processes take place. (p. 795)

The previously devised ecosystems provide context for the process of change, but the characteristics of the individual are given much greater attention. Individual traits include *demand*, *resource*, and *force* characteristics. Demand characteristics can be described as the physical characteristics that act as a stimulus to other people that may translate into expectations; resource characteristics are intangible mental and material resources available to the individual that may be assumed by others based on demand characteristics; and force characteristics are individual dispositions that can predict different rates of development. In the case of a person with mobility disability, the visible physical impairment, along with age and overall health can be categorized as demand characteristics, and resource and force characteristics, which may include educational attainment and a desire to exceed expectations, are likely to have an effect on the personal and professional development of the individual.

***The concept of time in ecological research.*** In his early writings on ecological systems, Bronfenbrenner cites Glen Elder's *Children of the Great Depression: Social Change in Life Experience* (1974) as an example of promising ecological research. Elder studied two separate cohorts of children born at different times during the Great Depression and sought to understand the processes of human agency that resulted in differences in their life courses. More recently, Campbell, Pungello, and Miller-Johnson (2002) used the ecological model to examine the impact of early childhood factors and family conflict in adolescence on the development of self-worth and perceived scholastic achievement in African American teens from low-income families. Both of these studies take the ecological systems of participants into account while allowing for

individual differences. The treatment of time varies in the sense that Elder's study finds differences in outcomes based on historical changes, while Campbell et al. find that circumstances during adolescence rather than early childhood predicted self-worth. Both examples provide guidance for future longitudinal research of mobility disability, including analyzing historical events like social security and healthcare policy changes, and personal historical events like the age at which the person becomes disabled.

### **A Model of Mobility Disability within an Ecological Systems Framework**

Given the framework of embedded systems, this model will look very similar to the general ecological systems model, but pays particular attention to how having a mobility disability might impact a person's microsystems, including a greater presence of health care professionals or physical therapists. It will also give special consideration to relationships involving transportation, government policies, healthcare, financial security and social opportunities. In the macrosystem and chronosystem, societal attitudes, federal policies, and perceptions and portrayals of disability could also have a relationship on the interactions within smaller systems. People of different ages will have unique experiences in relation to historical events. The following diagram (Fig. 2) outlines potential themes that apply to mobility disability within an ecological systems framework. The person has a presence in all of the microsystems that apply to their unique situation, and the other dots represent people whose presence or absence can have a positive or negative impact on the individual. All of the microsystems also have physical characteristics that can be considered as variables in future models that involve interactions within and between systems.

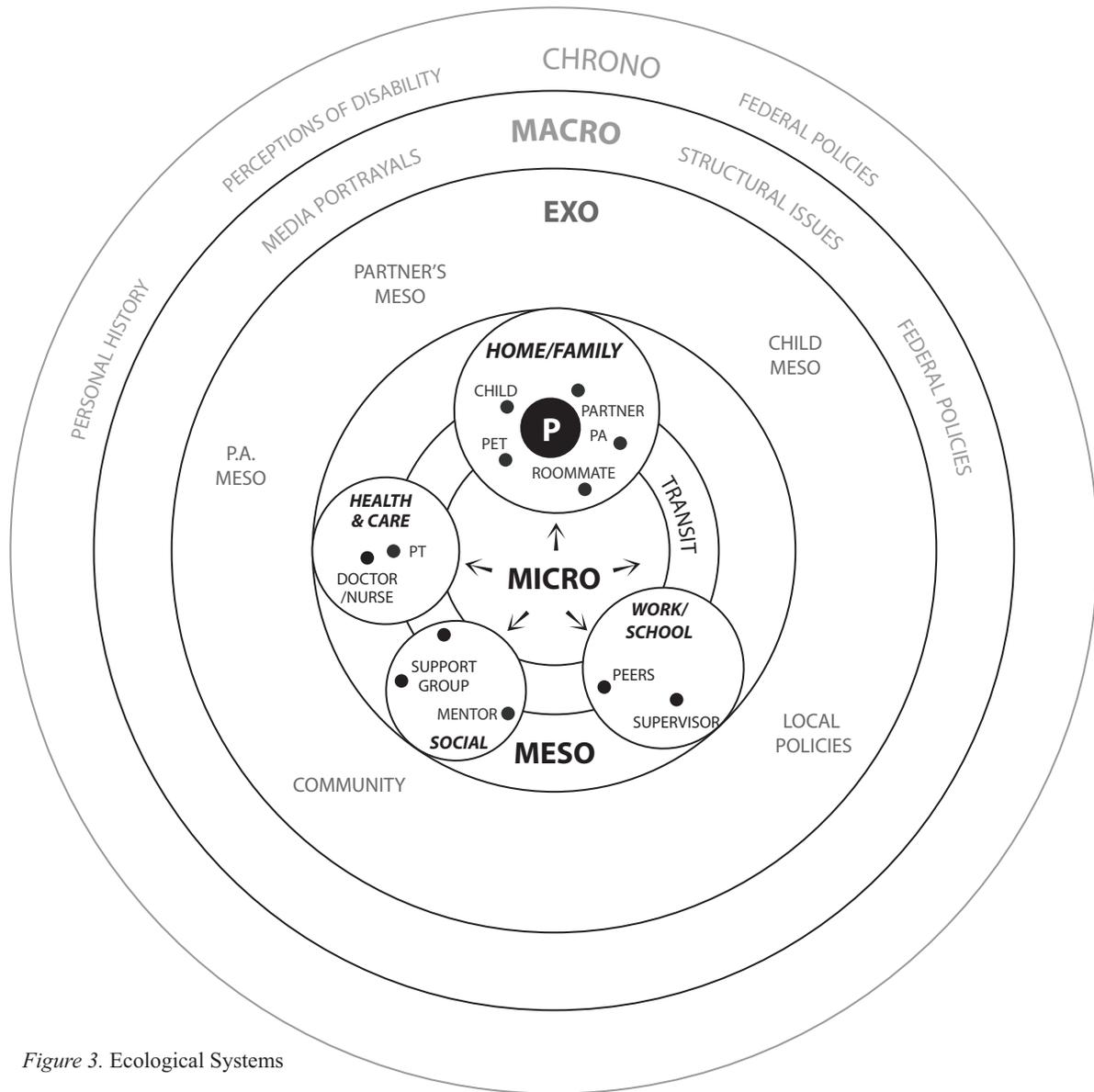


Figure 3. Ecological Systems

The next diagram (Figure 3) outlines relevant themes in the Person-Process-Context-Time model with mobility disability in mind. These four categories are the themes used to explore the data that was collected in the pilot study. The next chapter outlines the relevant person characteristics, proximal processes, context and history for the people who were interviewed.

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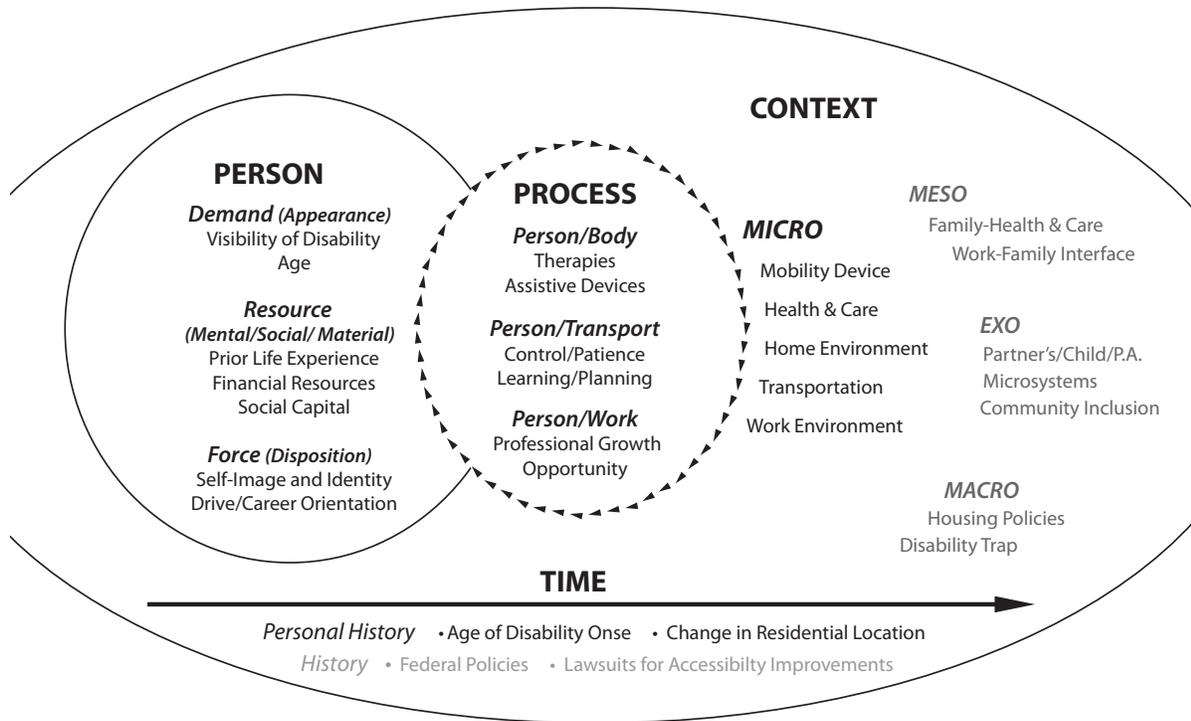


Figure 4. Person-Process-Context-Time Model

### **Chapter 3: Dimensions of Living with a Mobility Disability in New York City**

With theoretical and methodological frameworks in mind, important insights can be taken from research on work-family and disability studies. After reviewing transcripts from interviews, a model of important ecological factors for people with a mobility disability takes shape.

#### **Person**

In the most recent ecological systems theory, more attention is given to the individual within the context of the various systems. The process of development is largely influenced by certain characteristics of the person, and can have a positive or negative impact on rates and direction of change.

**Demand characteristics (appearance).** Demand characteristics are described by Bronfenbrenner and Morris (2006, p. 812) as having the “capacity to invite or discourage reactions from the social environment that can disrupt or foster processes of psychological growth: for example, a fussy versus a happy baby, attractive versus unattractive physical appearance, or hyperactivity versus passivity.” The physical characteristics of people with mobility disabilities certainly have the potential to shape their developmental processes, which will be discussed later.

**Visibility of Disability.** Mobility disability is often a visible disability because of the presence of assistive devices. All of the disabled participants in the study used a wheelchair or scooter, and in most cases, the powered chair users also had limited upper body mobility. The use of a wheelchair often prompts questions or comments from people in public, which was a recurring theme in many interviews. Many of the participants described feelings of stress related to comments from strangers when using public transportation:

George: The biggest issue is with the attitude of the folks that are on the bus. So,

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the bus driver has to pull over, stop the vehicle, get out of his seat, and in New York City, everything is (clap, clap, clap). You know? And so, by the time you're actually rolling onto the bus, I mean, people are looking at you, like you're... 'How dare you? Slow down our progress...' Whenever I rolled on a bus, I'd hold my eye—I'd always look down to the ground because I could not look people in the eye. And, it was humiliating.

Other participants noted comments about unsolicited prayers and blessings:

Alexandra: The religious piece is something that's always really interested me. People say, 'Well, I'm going to pray for you.' Or, 'God bless you,' and they don't know anything about me, they don't know my religious views, they don't, you know? But, that's very attached, in—potentially, in their mind, too. Or if someone—I've had people getting to know me a little better, seeing me smile, and saying, 'Wow, you must be really a person of God,' and I'm thinking, 'I'm actually not...'

She also mentioned being mistaken as begging for money when asking for assistance with a door:

There are times when I'm like standing outside of the door, and will be waiting and ask, 'Can—sorry, can you grab...?' You know? And sometimes people say, 'No, I don't have any money for you,' which is really... funny, and an interesting experience.

The type of wheelchair used can also lead to certain assumptions. Angela talked about the feeling of being stereotyped based on her powered wheelchair:

Angela: Just because I'm on a power wheelchair don't mean I have money. Um, because, I've been with people in [hospital] in manual wheelchairs, they don't

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treat them like that. But, when they see me on a power chair, they look at me like I have money. I'm like, 'I don't have money. Just because I'm in a power wheelchair and not in a manual? Automatically I have?'

In the same way, upper body mobility limitation leads to assumptions about abilities that may make it difficult for people to get past immediate judgment. Despite the success of many people with little to no upper body mobility, biases based on physical appearance are still present. Sofia, a quadriplegic who earned a bachelor's degree after an injury described this hurdle in searching for a high-paying job:

If I go to work or something, I have to make sure that I get a truly good, well-paid job to pay for my stuff. Or, else, they'll take the SSI away. So, I'm trying to prepare myself—I went to college. To get a job in this condition, it's hard.

In cases of a self-care disability, the presence or absence of a health care aide may also elicit different reactions from strangers. Angela described an experience on the bus, implying that the presence of her aide may have deterred negative comments from a stranger:

I remember one time, we were in the bus, and a guy just came up—he didn't know my aide was with me, and he goes, 'Ugh, here comes a wheelchair,' instead of saying, 'A person,' he says, 'Here comes a wheelchair, now I'm going to be *late*,' and this and that, and you know, I have to go home, *too*, I have to... Let's say if I was to work, go to work, *too*, 'Seriously? You're going to be mad at me because I'm taking public transportation?'

**Age.** Another demand characteristic that affects reactions from strangers is age. Because mobility disability increases with age, responses may be tied to this expectation. George, an activist who is trying to form an alliance with groups working on issues for senior citizens

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described his encounters with elderly people rejecting the disability label:

If you talk to a senior citizen that clearly has a mobility impairment, they will say to you, 'I'm not disabled! I'm just getting old.'

On the opposite end of the spectrum, young people with physical disabilities didn't match up with this expectation:

Alexandra: I think it is, it's still surprising for people to see a younger, you know, I'll say, somewhat attractive person who is happy in a wheelchair. I think that is still something that is—there's a disconnect there, and it's confusing, and so, there is a desire for curiosity, or, wanting to know what is happening, and how and why. Which I can understand.

**Resource characteristics (mental, social and material).** Bronfenbrenner's bioecological model describes resource characteristics in terms of assets; "ability, knowledge, skill, and experience that, as they evolve over most of the life course, extend the domains in which proximal processes can do their constructive work," and liabilities; "conditions that limit or disrupt the functional integrity of the organism" (2006, p. 812). Resource characteristics include access (or lack of access) to housing, food, and education. For this study, I've grouped resource characteristics into three categories: socioeconomic status, work experience and skills, and social capital.

***Socioeconomic status.*** In analyzing the experiences of participants, socioeconomic status seemed clearly divided into two groups; those with financial resources and those without. Participants with financial resources still generally described difficulty in covering disability-related expenses, or being forced to choose residential locations that were more expensive than they were comfortable paying because of the accessibility or proximity to work. On the other end

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of the spectrum, participants like Sofia often found themselves making difficult decisions in relation to seeking employment and qualifying for necessary government assistance.

*Importance of family support.* For most participants, there was at least one mention of family financial support, either from immediate family who they lived with, or who lived nearby, and from family in other locations:

Alexandra: It's either you're really reliant on the systems and receiving Medicare, Medicaid, which means you're probably not working, or you have financial support in order to work and pay what you need. I mean, together, my husband and my income is easily six-figures, but we would not be able to afford the wheelchair stuff, and this apartment without my family's support.

Other forms of family support included shelter during transitional phases and assistance in navigating the complex bureaucratic processes of applying for disability and social security benefits. In one case, the partner of the person with a disability also provided caretaking for part of the day. Others drew a line at depending on their partner for personal care needs, making the availability of assistance even more important for the group that required personal assistants.

*Work experience and skills.* The distinction of socioeconomic status was often tied to prior work experience and skills. For some on the low end of the economic spectrum, their injuries came before they could acquire substantial work experience, or their previous jobs were physical in nature, leaving them no option to return to their jobs. For those with greater financial resources, most had prior education and work experience that proved beneficial in their ability to work or continue their self-employment. Other participants who were on the higher end of the economic scale were self-employed, either continuing their previous self-employment, or finding ways to fund their advocacy efforts.

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*Social capital.* While there is not a single definition of social capital, the Organization for Economic Cooperation and Development (OECD) defines it as “the links, shared values and understandings in society that enable individuals and groups to trust each other and so work together,” (Keeley, 2007, p. 102). One participant detailed a fellowship opportunity coming out of school, which led to finding her previous job in New York:

Alexandra: So, it's a—basically, nine month experience where you do rotations in each sector. It's also a really powerful network, and, so that helps a lot. You also have experience having these six jobs during that nine-month period, and so your last—they're called placements, your last, kind of rotation, you set up independently. And, so I set it up through a company that I had been really interested in that's focused on business and ethics. And so I started with them, and then they hired me full-time after my fellowship ended.

*Support groups.* Support groups were a common link for many of the participants. In addition to being able to share experiences and get advice, some people described the feeling of being an important support to others in the group:

Jessica: Have you been going to the support group for a long time?

Prentice: Not that long. I used to drop in and out. But, what I realized is, you know, some people—it's not about me. Some people might need to hear what I've been through or see—hear what I've been through and see where I am now. You know?

In addition to being able to bond over shared experiences, Sofia described the need for support from other quadriplegics:

It comes to a point, that, the people that surround you that they're able-bodied

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people, or maybe, like in my position, I got tired of them always—I felt like that I was an obstacle for them, because they had to maybe, carry me, or the wheelchair, or this or that.

Jessica: Oh, your friends and family?

Sofia: Yeah! So... it was always an issue. *Always* an issue. So, now that I started the group and everything, they're more active. It's weird that they're more active. They do *better* stuff, *fun* stuff, we talk about our problems, and it's cool, because everybody has the same problem. And, it's more... educational for me—I don't know. I just find it better.

*Mentors/mentees.* While several participants mentioned having a mentoring role for other wheelchair users, only one participant (who was one of the mentors) mentioned having a mentor:

George: She's the one who actually encouraged me to start competing. And, so at some point, when I kind of kept on placing in the top five throughout the country, she said, 'You need to do something a little different, you know? You need to do something a little more challenging,' and then I got involved in triathlons. And so, she was my mentor, believe it or not, in athletics.

In most cases, the mentoring was for people who were newly injured and learning to adapt to a new way of life. All of the participants who mentored viewed it as a positive part of their life, and welcomed more opportunities for mentoring.

**Force characteristics (disposition).** Force characteristics are the character tendencies of the individual that can have a large part in shaping their development. These may include a proclivity towards persistence that can translate into drive and career orientation, or self-image and identity characteristics that motivate actions and set processes in motion. Force

characteristics can also be deficits that could slow proximal processes and impede development.

*Self-image and identity.* Perceptions of self and identity were important themes that came out in the interviews. There were several main identities that were common or repeated, and nearly every participant had a unique take on their disabled identity. Family role was another shaper of identity for parents, and for some participants, their identity as a citizen and as a New Yorker were also important parts of their experience.

*Identity as a disabled person.* There were subtle differences in disabled identity throughout the group. This may be a function of the time of disability onset, which will be discussed in detail under the *Time* heading in this chapter. For Mary, a teacher who has been a wheelchair user for most of her life, her identity was not aligned with how she thinks society views disability:

Mary: I tell my students this all the time, 'Hopefully, you will live long enough *to* become disabled. Hopefully, you're going to have a disability someday, because it means that you'll live long enough to have your body...'

Jessica: Deteriorate?

Mary: Yeah, exactly. It makes people uncomfortable, because we still see disability as a horrible, negative fate, you know? And that's partially because of the media, and the way things are portrayed. I've had so many people come up to me, and say, 'I'm so *sorry*. I'm so sorry that you're in a wheelchair.' And, I want to say, 'I'm not! I can get down the sidewalk faster than you can!'

For Angela, who became disabled nearly five years ago, there was a desire to detach herself from the label of disability; she disliked pity from her partner, and described how they both rejected the term with family and friends:

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That was the one rule I give to, um... 'Don't treat me like I'm disabled.' Like, a lot of people would see us, we'll talk and everything's normal, like, if we argue or whatever, that's, that's the way I am— he's like, 'Wait, wait wait wait wait wait... *calm* down. That was the one rule my wife had, so, *never* treat her like she's disabled. Don't feel sorry for her because she won't talk to you. Don't feel sorry for her, she doesn't like that.' I don't like pity.

*Family role identity.* For participants in relationships or with children, identity as a provider and caretaker was important. In Sasha's case, this translated into a desire to find ways to adapt to activities and spend time with his children:

We have a bunch of activities I do there with them, so some of the things, I'm more just kind of watching, like when they're on the slide or climbing up a structure, I don't really do that with them, but I play baseball with them and I can pitch and field, and swing a bat and stuff, and so I've actually found a bunch of activities that work, that we can do together. So that's probably the biggest thing that I do... stuff with my kids, and physical therapy and exercise.

*Identity as a citizen.* There seemed to be a divide along socioeconomic lines in terms of opinions about current events, environmental problems or policies. For those on the lower end of the income scale, there was a general opinion that the government is doing the best it can, that accessibility improvements were costly, and that they were slowly making progress. For people on the higher end of the income scale, there was a mixture of frustration and outrage at the slow rate of progress. The mention of paying taxes came up more for this group. For example, Alice, whose husband has primary progressive MS, describes the parallels of her husband's accessibility issues and her experience trying to care for a young child:

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Alice: Yeah, yeah. The nannies of New York, and the moms of New York are... When we moved here, it was really ironic because we had to give up our nanny in Williamsburg because now she has another baby in Williamsburg, and because we can't get to her on the subway. And it was so interesting, I'm moving for Jason, and then we were having this other added burden because... it was like a double whammy to me. Actually, at that moment, I thought, 'Who is the subway for?' You know what I mean? It's not for me, it's not for Jason, it's not for [child]. And we pay taxes.

*Identity as a New Yorker.* Six of the participants were born and raised in New York City. This identity was generally described with pride, and for Sasha, this figured very strongly into adapting to life after being injured by a falling tree branch in Central Park:

I like being able to take the subway and it makes... both because it's faster, it's more... I think the biggest thing is, it makes me feel like a normal person. It makes me feel like I used to... I mean, I've used a wheelchair now for four years, four and a half years, and it kind of brings me back to, 'Oh wait, this is how I get around New York.' I grew up in the city, that's how I'm used to... that feels right.

*Drive/career orientation.* Four of the interview participants were currently or previously working full-time or part-time or on a volunteer basis in advocacy and support for disability issues. For George, becoming a mentor exposed him to problems in this area:

So, I started mentoring people in the hospital setting/rehab setting. And that's when I learned about the issues with accessibility and housing throughout the disability community.

There was also a strong sense of drive among these individuals, with two participants holding

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multiple advanced degrees. Some also participated in athletic competitions, and were active in local and national political organizations. Alexandra describes her full-time job at a nonprofit (that was not advocacy-oriented):

I mean, it always has its challenges, and it's a lot of hours, and a lot of hard work, but that's—I think I love being busy, and that's a great thing, too. I really enjoy the gray area in between sectors, and this is right in there. Say, 'Okay, how do we harness and leverage the resources that companies have for the social good?' That is challenging and exciting, and also a mission that I can get behind.

Part of this drive may be a result of both social and environmental cues that put them in a position to have to outperform in order to compete with nondisabled peers:

Mary: It really is required—to be the best student. You have to be down in front, sitting in the front, you can't be sitting in the back, you know, kind of dozing off. You have to be—you're up front.

For participants that were not working, drive was often related to earning money, and less related to career-oriented goals. One participant was looking for part-time work, and some described earnings in an informal market, though the details were vague. For Sofia, there was a drive to earn money, but she had to weigh losing the consistency of benefits in order to find a steady job:

Sofia: Like I said, you can—even if you make your money on the side, they'll take away whatever is steady, and you don't *have* anything steady. Today, I could sell a banana, but maybe tomorrow, they don't want to buy a banana. Do you get what I'm saying? But, I know that my SSI check is *every* month. You know? It's hard for us. And, I have a college education.

Jessica: If you still were able to get the SSI and have a job, and it didn't matter...

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Sofia: I would *love* to have a job. Because it would be *more* income for me—I *need* more income. I need—definitely, we *all* need more income, it's not enough.

### **Process**

*Proximal process* is the term Bronfenbrenner and Morris (2006) use to describe the ongoing reciprocal relationship between the individual and the immediate environment, people or symbols in individual microsystems. These sustained and repetitive processes translate to development over time, and the assets (or lack of assets) mentioned in the personal characteristics have a direct impact on these processes.

**Person/Body.** Separating the mind and body has been a philosophical discussion for ages. Embodiment is an especially important aspect of mobility disability, worth focusing on within the ecological system. Chronic illness or permanent disability also demand more time for health and rehabilitation.

**Physical therapy.** Nearly all of the participants with a spinal cord injury were working towards improving or maintaining their physical functioning. Physical therapy was a major part of their schedule, whether they were working or not, but the location, convenience, and availability of services were better for participants on the high end of the economic scale. For those on the lower end, transportation added significantly more time in getting to the facility for therapy, so they went in for sessions twice a week. Some participants with a decade or more since their injuries described a recent or renewed interest in therapy. Prentice described improvement since first being injured in an auto accident along with his motivation for continuing physical therapy and becoming more self-sufficient after moving in with a girlfriend:

Prentice: [Then], I wasn't able to fend for myself ... now I can fend for myself.

I'm the man of the house now, you know what I'm saying? So, I can't just, depend

on—I don't want to do that, depend on my girlfriend all the time—she's my girlfriend, she's not my nurse, you know what I'm saying? So. I pretty much can do for myself. As far as anything that has to do with my mind. Physical is a different story, but we're working on it.

Most described positive feelings about their therapy. When asked about the possibility of trying assistive devices like exoskeletons, Sofia expressed a lot of interest and described the feeling of standing during physical therapy:

[W]hen I go to therapy, they stand me with a standing frame. And, I'm so happy, to be in—put in something, and for at least a while, just to be *walking* around, even for an hour.

The frequency and proximity of therapy facilities would be important variables to consider in future research designs.

***Drugs and treatments.*** Two of the participants had chronic diseases with available disease modifying treatments. For spinal cord injuries, stem cell treatments are being explored, though they are costly and in very early stages of development. Sofia described others' skepticism of the efficacy of stem cells, and her own experience with experimental treatment:

Sofia: I believe in stem cell research.

Jessica: Stem cell research? Yeah.

Sophia: I've actually had the opportunity to get them. Twice, already. And, it has made a difference in my body.

Jessica: Oh, really? So, you've done that twice? Do you want to do more therapies?

Sophia: Yes. They're sponsoring me to do that, and whatever they want, I'll do it

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because I really do feel the difference.

Jessica: Have you recommended anyone else to do the same treatment?

Sophia: No, because a lot of people are very skeptical. And, they will all say, 'When you walk...' and I'm thinking, 'Whatever.' I know what I'm feeling, I know what I'm doing different, I know that, I'm improving, and that's important to me.

**Person/Transportation.** Transportation choices varied greatly by location, and many stayed within prescribed routes more often than going to other parts of the city. All of the participants described adapting to unique challenges presented by different transportation options.

***Control and patience.*** For many people, transportation involved learning to be much more patient, a behavior that is antithetical to the fast-paced atmosphere of New York City. The theme of control came up often, usually in terms of a lack of control over certain circumstances.

Allowing more time before appointments or meetings mitigated unexpected delays:

Sasha: I'm constantly learning how to make plans more... that I'm less likely to be disappointed with myself, and leave people who are relying on me hanging, you know, my kids, my friends, my family... I guess my biggest thing would be just that you just kind of need to infinite... it seems infinite sometimes, but it's not infinite...but you need to really be much more... things just take a lot longer. You need to just say, however much time you think it's going to take to go somewhere or do something, you just... need to understand that it's going to be double or triple, or could be a lot longer.

Other coping strategies involved choosing a transportation mode that was most reliable. For people with higher socioeconomic status, taxis were a preferred method, especially at a specific time of day or in wet weather conditions. Taxis were out of reach for the people with a very

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limited income, so Access-a-Ride was usually their preferred mode. Three participants had their own vehicles (including the out-of-town participant), and one was trying to secure a van in order to have reliable transport in order to search for a part-time job.

***Learning and planning.*** In addition to choosing more reliable modes of transportation, there were several participants who took advantage of limited subway access for specific routes; mainly between work and home. The majority of participants didn't attempt to take the subway, or only did so as a last resort. A few people were afraid of not being able to get out, or were afraid of crowds and impatient people. Of the participants who used the subway, all of them described experiences where they checked elevator status, but still found out-of-service elevators, had to travel to another station with an elevator, or backtrack so they could exit the system. For Sasha, taking the subway in a wheelchair was a very different experience:

So, both the cabs and the subway are things that I initially didn't do just because they're more difficult, so I had to learn how to do them, and kind of figure that out... So, I've kind of learned in the subway, as I was telling you, which... I've learned where to wait on the platform, so that part of the platform, the kind of lip between the platform and the subway, the open door is minimized, so there are some places where you can roll directly on, it's totally flat, or I just have to do, like a slight wheelie. And there are other parts of the platform, you can see it; when the subway's pulling into the station, how high it is from the platform to the subway. And, there are other parts where the lip will be 2, 3, 4 inches, to a point that I really can't get on it, so, but... When I was first starting to do it, it happened a few times that I would get up to the door, and I just couldn't, like... I would wheelie up and I would just kind of bump against it. And, if other passengers saw

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that, they would always kind of grab the door and help kind of... push me on... push me on/pull me on, and it's kind of amazing that there's just always somebody that would do that.

Most of the participants felt that the density of New York City allowed for some flexibility in transportation that other cities would not. For Sofia, who typically relied on Access-a-Ride, other transit options were a good backup in case something went wrong:

I would guess there's ambulette service, but I mean, you... here, could have an A, B, and C plan. Over there, it's hard. To have a backup.

**Person/Work.** Work also required adaptation in different ways. For some participants, there was a need to learn new skills or learn how to use assistive technologies. Two participants described receiving computer training through ACCESSVR (formerly VESID) to help their chances of finding work through recruiting agencies. In some cases, work became slower because of disability, or hours were shortened to accommodate physical therapy.

**Professional growth.** Of the career-oriented participants that I interviewed, none were in supervisory roles, most likely due to the young age of one participant, and the part-time status of the other:

Sasha: I've never managed other people, I still don't, but, um, but before I was disabled I was, kind of like, in charge of a project, and now I'm... but, now I'm just, I'm a team member, and have responsibilities in the project, but I don't set the direction of it.

Both people still seemed content with their positions, and expressed a desire to stay with their current companies. For the self-employed participants, there was a drive to continue education and achieve goals.

***Finding opportunity.*** People with disabilities are typically underrepresented in managerial positions, receive lower wages and training, and are less involved in decision-making (Schur, Kruse, Blasi, & Blanck, 2009). For the two participants who worked for an employer, both did their work in an office, and liked being in a workplace as part of their routine. While one person returned to his job after an injury, the other had been using a wheelchair for some time before interviewing for her current position. In her case, she believed that her prior advocacy experience on her resume made the question of if and when to disclose her physical disability unnecessary. Another participant was searching for a part-time job through ACCESSVR, a vocational rehabilitation agency that helps severely disabled people find employment, likely disclosing the disability in the process. The issue of disclosure is a widely discussed topic on LinkedIn disability employment groups. The timing of when to disclose is an issue for people who need accommodations, especially during the interview process.

### **Context**

In the ecological model, context refers to all five levels of the ecological system in which the person is embedded. Microsystems comprise of direct relationships between the person and people or environments that immediately surround them at different points in time. The mesosystem consists of the interactions and relationships between variables within these domains, where the work-family concept is relevant. The exosystem includes the mesosystems of other family members, as well as structural factors that may impact the person indirectly. The macrosystem includes larger federal policies, social issues and perceptions of disability.

**Microsystems.** The variables within unique microsystems include people, objects and symbols that influence the proximal processes discussed in the last section. For the purpose of context, environmental factors will be outlined in the following sections, with additional context

for unique mobility concerns.

***Mobility Device.*** Of the eight participants with mobility disabilities, three used manual wheelchairs and the rest used powered wheelchairs. When I asked the powered chair users about the process of finding a good chair, most responded that they were generally satisfied from the beginning. They also had a manual wheelchair as a backup, or to use when traveling. Maintenance for powered wheelchairs was another issue that seemed to split along socioeconomic lines. Participants who were enrolled in Medicaid described long waiting periods for repairs, and in an extreme case, one surrendered her chair to be returned weeks later, severely limiting mobility during that time:

Angela: I repaired it only twice.

Jessica: Only twice, yeah. And, were those both because of weather?

Angela: Yes. So... one was snow, one was rain. But, um, a lot of little stuff, like, um, the *hand rest*, or little stuff like that, I do it all the time.

Jessica: Get it fixed?

Angela: Yes. I have to have it fixed all the time. Right now, that one is *really* loose—the hand rest. It's *really* loose. But, I'm afraid when I give it to them, they're going to keep it for a *while*.

Jessica: Oh, they take it?

Angela: Yeah. They come and pick it up and they stay with it for months. Weeks, months at a time. I do—I'll tolerate days, but *weeks* and *months*?

For one participant who was working full-time, maintenance was performed on-site at her home, but she also described frustration with large windows of time when a repairperson was supposed to arrive, along with the need to coordinate with another person to lift her out of her chair

because they weren't allowed.

***Finding stability and comfort.*** For many participants, a lack of privacy in non-accessible apartments was a concern, especially when they had to stay with family members or couldn't get into bedrooms. Many had gone through the process of searching for an apartment, and were unable to find important information about accessibility (even basic details about steps to an entrance or steps within the apartment). George described encounters with people he mentored:

In a lot of cases—the front entrance is not accessible. In other cases, when you go into these buildings that were created after WWII, then the entrance may be accessible, but you always have steps on the inside to get to the different levels. In every single one of those units, the doorways are so narrow; they can't even enter the bathroom. Or go into the bedrooms, a lot of them live *in* a living room space, and they kind of have to take a birdbath inside the living room space. It's horrible.

One person described starting the hunt when she and her husband decided to move, and eventually settling for a place and landlord that they knew would be accommodating:

Alice: We were looking for an accessible—I mean, reasonable accessibility because we knew what we were up against. So we, you know, we'd pay a ton more to have an accessible space. Before I met Jason, I lived in walk-ups and saved a lot of money that way. I started with a broker and told him my parameters, and he was good. But then, we finally—we wanted a known quantity, so we came back to this building. Because we know they're super slow, but they eventually do stuff. The devil we know was sort of better than the devil we don't.

***Home environment; choice and satisfaction.*** The topics of choice and satisfaction rarely came up in discussions about accessible housing; in fact the *lack* of choice was more typical,

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along with modifications or adjustments to existing living situations. One participant who owned his apartment relayed his frustration in being forced to renovate the unit in his new building to include an accessible bathroom, and the difficulty in finding an accessible unit that wasn't on the ground floor:

Jessica: Were there any units in the building that were actually accessible?

George: Yeah, there were. 5% of the units were accessible. They were available, but none of them had a terrace, and they were much smaller than this apartment.

So, I, I wanted to be able to have...

Jessica: Do you think the developers are also doing, like...? I mean, I've heard about this, when they have requirements to make a certain percentage available to low income people, it's the least desirable units in the whole building.

George: That's what they did here. So, I—the developer—I'm friends with the owner of the company of developers. He said to me, 'George, we did a study to see what the average person with a disability in New York can afford. And, according to the study, if you have a mobility impairment, you can't afford an apartment with a terrace.' What kind of shit is that?

Another couple described a recent purchase of a house outside the city that was being renovated to provide accessibility for the disabled woman. They both gave excited descriptions of comfort, privacy and access to all parts of the home, features missing from their current living situation.

***Transportation.*** Questions related to transportation addressed mode choices and experiences, whether it was transit to work, physical therapy, social outings, or other obligations. Participants all described adaptations to their travel habits based on their financial resources, time availability, and location. For the participants commuting to work, each had a different

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strategy to take advantage of the most reliable route, whether the weather allowed for a pedestrian mode, or taking a taxi because it was the fastest.

*Sidewalks.* The prevalence of curb cuts in New York City has improved since the Architectural Barriers Act of 1968 was passed, but for many wheelchair users, the lack of a single curb cut can be a barrier to independence. After settling a nearly decade-long lawsuit from the Eastern Paralyzed Veterans Association (EPVA), the DOT agreed to invest \$213 million in pedestrian ramps throughout the city (Ross, 2012). According to the DOT website, “the City has installed pedestrian ramps at 97,664 locations (reflecting 61.5% of the City's 158,738 corners)” (“Pedestrian Ramps,” n.d.). This figure supposedly includes 80% of Manhattan curbs, but it’s difficult to verify, and is a claim that hasn’t been updated since 2004 (Silver, 2004).

The DOT website also states that by New York law, property owners are required to “at their own cost, install, construct, reconstruct, repave and repair the sidewalk adjacent to their properties, including the intersection quadrant and pedestrian ramps for corner properties, in accordance with DOT specifications” (“Questions & Answers to Common Sidewalk Violations,” n.d.). Violators will be ticketed, and they can make improvements themselves, or let the DOT make the repairs and send them a bill. Receiving a citation is sometimes surprising for building owners, and the gray area of accountability confuses even local pedestrian advocacy groups calling on DOT to repair curb cuts and ensure smooth sidewalks (*East Side Action Plan*, 2011).

Sidewalk quality was seen as a relatively minor concern, but most still described corners they passed frequently that weren’t accessible and modified their walking routes accordingly. Several people used the street or bike lanes to avoid cracks or bumps in the sidewalk. Precipitation was a problem for powered wheelchair users, and un-shoveled snow was especially difficult to navigate:

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Jessica: You don't have problems with the curb cuts anywhere?

Prentice: Not all the time. Sometimes I like to stay in the street anyway, avoid the bumps in my wheelchair.

Jessica: Stay in the street?

Prentice: Yeah, avoid the bumps. I can go full-speed where I need to go.

Jessica: What about snow?

Prentice: Well, that sucks. This past winter, we probably had two storms, two or three storms, and I was stuck in the house both times, because, the snow is crazy.

And I couldn't—not everybody shovels the sidewalk in front of their house on the block. So, everybody could be shoveling snow, and it will just take one house, one guy not to shovel in front of his place, and I can't get past because of the snow. I mean, that's when it's high, you know. And it sucks.

*Taxis.* The use of taxis varied, and was almost exclusively available to the people who were on the higher end of the economic scale. For several people, it was an important mode choice in cases of bad weather, when going longer distances, when making spontaneous trips that were not part of frequently used trips on public transit, and as a backup when public transit plans failed. Finding a wheelchair accessible taxi was not necessary for two people who used manual chairs, and could put their chair in the trunk, but for powered chair users, they could call a dispatch service to send an accessible cab within a short period of time.

The fight for wheelchair accessible taxis is still unfolding. After a lengthy legal battle, several individuals and advocacy groups won a class-action lawsuit against the Taxi and Limousine Commission (TLC) (Klasfeld, 2011), which was later turned over on appeal. The Taxis for All Campaign continued legal action, and the city decided to settle and agreed to

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require that half of TLC's fleet be wheelchair accessible within six years (Weiser & Flegenheimer, 2013). A 30-cent surcharge was recently approved by the city council to help cover the costs (Flegenheimer, 2014). Ironically, recent competition to the TLC from private interests such as ride-sharing company Uber, may improve accessibility requirements even more. A letter to the district court from The Committee for Taxi Safety even seeks to require 100% of the car-for-hire industry become wheelchair accessible (Hutchins, 2014).

*Subway.* As part of an agreement with the Federal Transit Administration (FTA) in 1992, the MTA agreed to make 100 key stations accessible by 2020, but are under no obligation to make the system completely accessible (*Rapid Transit Services for Persons with Disabilities*, 2004). Assuming you could travel from any single station to any other single station, and using a simple equation  $(n)(n - 1)/2$  to compare the number of station-to-station trips for 100 accessible stations vs. the total 468 stations in the system, people with ambulatory disability will be able to make about 4.5 percent of possible trips (4,950 out of 109,278). A more in-depth analysis of ridership by station would be required to weigh the impact on those with mobility disabilities who live near key stations.

During an audit performed between 1994 and 2002, NYC Transit noted the absence of wheelchair users in the system, and identified a number of areas that weren't ADA compliant, including excessive gaps between platforms and cars, incorrect signage, out-of-service elevators, a lack of elevator redundancy, and no notification system for non-functioning elevators (*Welcome Aboard, Accessibility at the MTA*, 2008).

Even for stations with elevators, other barriers still make them inaccessible. In 2008, 167 elevators and 169 escalators were plagued with problems, and one in six elevators were found to be out of service, with variation in parts, faulty construction, and poor technician training cited as

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reasons for the breakdowns (Neuman, 2008). Several years later, an internal report found that MTA had not properly managed its *out of system property*, 33 privately owned elevators and escalators, which break down frequently, remain in a state of disrepair for long periods of time, and are not accounted for on the MTA's list of non-functioning elevators (Kluger, 2011).

By all appearances, the MTA seems content to make key stations accessible, but not above the 100-station minimum. In two separate subway station renovation projects, they failed to include plans for elevators, or other considerations for accessibility. The first, the 1 at Dyckman St. in Washington Heights, was modified after a class action lawsuit, and an elevator on the southbound station was promised as part of the settlement (Zanoni, 2011). The second, at Smith-9<sup>th</sup> Street station on the F and G lines opened recently to disappointment, but no legal challenge as of yet (Kabak, 2013). The projects cost \$45 million and \$32 million, respectively, and MTA cited "prohibitive costs" as the reason elevators weren't installed.

*Access-a-Ride.* In order to fulfill the requirements of the ADA, the MTA offers alternative or para transit to passengers that live along fixed routes that aren't accessible. Because many of the buses only operate within individual boroughs, using public transit to travel between boroughs usually requires Access-a-Ride, so participants who lived in the outer boroughs were the most frequent users. Most had complaints about the time and energy involved in the process, which included scheduling rides and being available at the exact appointed time, even though they often had to wait for drivers who were late. Sophia described the exhaustion she felt after days she spent going for physical therapy:

Because, believe me, it's so long, to go to the city, every day, I'm thinking, 'Oh, *traffic,*' all of that.

Jessica: Yeah. So, how long does it take you to get there?

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Sofia: It's not that it's *long*, but you know, sometimes you have to pick up other people, and drop them off, if they... I get tired. I get tired. It can take a whole day. To go to the city and go back, for me, it takes the whole day. But, when I come home, I don't want to do anything. Lay down, and watch TV. Sometimes, I don't even want to talk on the phone. It's so tiring.

Other participants decided to find other means of transportation because of their own experiences with unreliable service, or hearing about it through other acquaintances. One participant described being interviewed about accessibility where they lived:

Yeah, I um did an article for the [blog], which is like the neighborhood blog, and they went around with me and kind of talked about accessibility in this neighborhood in particular, and one of the quotes, which I didn't realize would be resonant, was like, 'Well, Access-a-Ride isn't an option for me, because I need to be on time.' And so when I came back to the office, everyone was like, 'Access-a-Ride isn't an option for *anyone*. Because, *everyone* needs to be on time.' You know? Like, that kind of two-hour window, it can be helpful for some people, but it's—in the reality, and in the world we live in, that's not an option.

*Buses.* As a backup when other options failed, and for short trips, most people took the bus. Some felt it was more reliable than trying the subway, and others avoided the bus because of comments from other passengers. One even described his disabled partner being left at the bus stop on more than one occasion.

***Work Environment.*** For two participants who worked in an office, work environments were accessible with only minor accommodations needed. Another participant had taught at various schools and found that wheelchair accessible facilities were not the norm, and had to

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work harder for accommodation. For the two that worked in offices, both generally found their coworkers and supervisors supportive. None of the participants had experienced discrimination in their current position, but one described a past experience working in retail. Just as job quality can be related to autonomy, there may also be a connection between quality of work and disability-based discrimination:

When I was in college though, I did work a retail job, and I remember... I would come in—and I was only working maybe like, an hour or two a week, it was not even part-time, right? Um, basically, I was doing it for the discount—haha, as we all were—I remember though, that the accessible bathroom, they kept piling boxes up in front of the accessible bathroom. And, I would say to them, 'Hey, you know, I really need to go to the bathroom,' and then, they would move the boxes, and the next time I would come, they were piled up again. And, it—and this still stays in my memory—what it made me feel like was that they were trying to get rid of me. That's what it felt like. Because, whether it was true or not, it felt like they were basically saying, 'We don't want you to work here. So, we're just going to make it as inconvenient as possible.' And, that was the first time I truly felt discriminated against in a working situation.

***Health & Care.*** The individual health and care microsystems were unique to each person. The reason I separate the words is that for some people with injuries, help with care becomes a necessary part of their routine, and in cases where a personal assistant is necessary, one or more people can become part of daily life. Health is a concern for everyone with limited mobility, but some are also dealing with chronic diseases that may make the healthcare system a larger part of their daily life. These are all necessary considerations for future research.

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*Independence and need for assistance.* For participants with personal assistants to help them with their self-care needs, the accessibility of the bathroom was less of a concern. They still expressed that they would prefer to roll their chair into the bathroom. Of the eight participants, only two were able to get into their home bathroom with their wheelchairs. One made costly renovations on the apartment he owned, and the other lived in a new building with doors that were wide enough to accommodate a wheelchair.

Boundaries around self-care were an important theme for those that needed a personal assistant. Alexandra explained her decision to find help when she moved in with her husband:

I don't have a lift at home, and so either my husband helps, or I have a caregiver who comes—one person who comes in the morning, and one person who comes in the evening. And that was something that was new...in the past, I've—it's always been friends who have helped with that kind of thing, and I haven't needed as much help, and so, moving in with my husband, we said, 'This is—this will be important that you're not the only caregiver.'

Sofia similarly described keeping the caretaking separate from relationships with family members and partners:

Everything depends. Because, if you have a supportive family and they're with you, or you live with them, it's different. Obviously, not letting them do everything for you—because everybody's going to get tired. It's better to pay somebody, have somebody that works, and that's their job. Because, it becomes too much of a burden for the family and friends. So, not mix one thing with the other, even when you're having a relationship with a partner. They should know how to do everything for you, just in case, but not let them become your aide.

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**Mesosystem.** In Figure 2, the microsystems show possible forces within different immediate environments that may interact with other microsystems. This interaction between microsystems is known as the mesosystem. Mobility disability is an additional variable that could impact parts of the complex relationships between family and work, family and health-care microsystems.

***Work-Family Interface.*** For this limited study, having a job or being self-employed had a positive influence on the wellbeing of the person with a disability. This group described busy lives with social activities and not much free time. For people who were unemployed or looking for work, there was much less demand on their time, and many reported relaxing and resting when they did not have other obligations. Two unemployed participants described a desire for more social opportunities, enjoyed support group activities, and tried to see friends as much as possible. They also volunteered their time, one as a coach, and the other as a mentor. Other work-family themes that came up were the transition phase after becoming disabled and the flexibility of work schedules.

***Transitioning back to work.*** One participant was able to return to his previous job after becoming disabled.

Sasha: I got out of the hospital in spring of 2010, and then I came back to work about a year after that, so spring of 2011. And then, since then, I've sort of slowly stepped up, so at first it was one day a week, then two, then three, and now four days a week that I come into the office.

***Flexible Schedules.*** Sasha also described a flexible work environment that made his part-time schedule possible. In addition to accommodating his extended absence, he described an environment that was generally flexible for family or personal needs:

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I think I was fortunate in a lot of ways that this particular workplace is very flexible and adaptive to people's specific needs, you know, whether it be my case, or um, people with families, or people with, you know, various things... I think it depends a lot on your position, and it happens that those responsibilities I have aren't... they do work sort of well with a flexible schedule.

***Family-health care system/professionals.*** The daily presence of a personal assistant or assistants is a factor that should be investigated more thoroughly. For many people with limited upper and lower body mobility, having a personal assistant was essential, but the quality of relationships was mixed. Angela described the relationship with her personal assistant as like having a non-biological sister, while Alice likened her husband's P.A.'s to having roommates.

***Exosystem.*** At the next level of ecological system, the exosystem "comprises the linkages and processes taking place between two or more settings, at least one of which does not contain the developing person, but in which events occur that indirectly influence processes within the immediate setting in which the developing person lives" (Bronfenbrenner, 1994, p. 40). One example of the exosystem is the mesosystem of another family member; if the person's partner is experiencing stress at work, this may indirectly affect the person even though they are never physically present at their partner's workplace. Another example that applies to this group is the presence of a personal assistant, and the impact of their mesosystem. The exosystem can also be thought of as an ecological system where the individual is not always present, but is still impacted by changes in the environment or social norms. Inclusion in the local community can also be examined as an important exosystem for people with mobility disabilities.

***Partner's mesosystem.*** A flexible workplace was also important for one nondisabled participant who took on a caretaking role for his wife in the evenings and on weekends. He

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described the time period after his wife became disabled:

Jessica: Were your supervisors pretty understanding of your situation? Did they work with you pretty well?

Christopher: Yeah. Most of them did.

Jessica: Most of them? There were some that didn't?

Christopher: Only the warehouse manager. He didn't want—he didn't want me to change my hours. He was a real... douche. After a while, he told me it's none of his—he said, 'It's none of my business how your wife got like that, but you gotta go back to your old schedule.' I fought it with the union and everything. I ended up winning.

***P.A.'s mesosystem.*** Even if personal assistants were not always present, or close to every participant, their very presence is reason to consider them in research because of the intimacy of the relationship, and the necessity of their service. In the same way a partner's work may cause spillover into the home, a personal assistant's private life, or other professional commitments could spillover. Christopher described problems encountered when his partner needed a temp because the assistant was ill or took a day off:

Christopher: Yeah. Especially, like, there were times when her home aide doesn't *come*, and they send someone else. The office doesn't let them know that she can't walk. So, they come in, and they tell her, 'Alright, get on your chair, and go take a bath.' She's like, 'I can't get on my chair.' Then they're like, 'Oh, they never told me, I don't know what to do.'

***Community Inclusion.*** The local community where a person lives can also be considered an exosystem. Even though they may not spend most of their time out in the community, changes

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in the local environment are likely to have an impact on individual empowerment. The theme of exclusion from local businesses was more pronounced for people living in Manhattan. This could be a function of older buildings with multiple stories and basements. Most people called ahead when going to a new place to find out about wheelchair accessibility. Several people described experiences where their due diligence still wasn't enough, or figured out a way to get into places that weren't accessible with help from friends or family who could carry them. One participant described the dilemma this presented for her:

Alexandra: I'll call, because I've been burned too many times. I'll say, 'You said you were accessible,' and they'll say 'Well, yeah, it's one, one step, that's it,' you know? Still, no. Hahaha. I mean I would never leave this on the street (powered wheelchair), or bring a manual wheelchair, and there are some restaurants that are really great, and I want to be able to do that, but then thinking about, 'Okay, I'm financially supporting a restaurant that is purposely excluding me, is that a good thing to be doing?' I mean, luckily in this area, there are a lot of accessible restaurants, and so, it's not as if we're lacking variety, but, I certainly know which ones for the most part are accessible vs. not, and make those decisions of, 'Okay, should I have someone help me into a manual wheelchair, push me there, lift me up the step and then bring me back, and put me back in the wheelchair?' vs. going somewhere, that I can just go into by myself.

**Macrosystem.** Bronfenbrenner (1994) describes the macrosystem as “institutional patterns of culture, such as the economy, customs, and bodies of knowledge.” While there are many such concepts that can apply to people with physical disabilities, including media portrayals of disability and structural issues that affect social inequality; some government

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policies have a direct impact on quality of life for this group, and shape their daily existence.

***Housing policies.*** The socioeconomic disadvantage of people with disabilities affects their ability to afford housing, and a shortage of accessible housing can make matters worse. Funding for building development and accessibility regulations impact the ability to live independently for some with mobility disabilities.

*New York City affordable housing crisis.* The lack of affordable housing in New York City is impacting low and middle-income people, so more are looking to public housing, which bases rent on income. Last year, 277,000 people were on a waiting list for public housing, which had fewer than 6,000 openings per year (Navarro, 2013). The quality and stability of public housing is another issue. NYCHA estimates it will need \$18 billion for repairs just to make the buildings livable, and has a budget deficit is \$77 million this year (Navarro, 2014).

*Accessible housing crisis.* While the affordable housing crisis may be well known and covered in the news, the accessible housing crisis is somewhat under the radar. The ADA requires that just five percent of units in residential buildings for private ownership have accessibility features for mobility disability, and a minimum of one unit that is accessible if the building has at least five units (*Guidance on the 2010 ADA Standards for Accessible Design*, 2010). By the national census figures, five percent is short a half of a percent of what is needed, and there is no consideration for inaccessible units that are too costly to modify.

For many people in the 18-64 age range who become disabled, the unfortunate result is that they are moved to retirement facilities that can accommodate them. As of 2010, nearly 15% of more than 100,000 residents in Medicare or Medicaid certified nursing homes in NY State were under the age of 65 ("MDS Active Resident Information Report, RSaGE: Age of Resident," 2010). A local organization called Wheels of Progress estimates that there are 14,000 young

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people in retirement homes in New York City, and 600 newly injured people institutionalized every year. The median cost in Manhattan for a resident in a semi-private room was \$13,688, and the median cost for a home health aide is \$4,001 ("Genworth Cost of Care Survey," 2014).

In May, 2014, Mayor de Blasio announced a ten year plan to address the affordable housing crisis, including a 2% increase to the federally mandated 5% accessible unit rule for new developments (Glen, 2014).

There is a lot to celebrate for people with disabilities in the Mayor's new housing plan for New York City! For the first time, we are included--with recognition of both the need for accessible housing and affordable housing! See pages 84-85! –  
*Center for Independence of the Disabled (CIDNY) Facebook post, May 5, 2014.*

The city council also approved an increase on the income limit for individuals and households seeking a Disability Rent Increase Exemption to \$50,000. Prior income thresholds for residents paying more than 30% of their income for rent were \$20,412 for single people, and \$29,484 for households ("DRIE Information for Tenants," 2014)

*The 'disability trap.'* Mobility can also be theorized in terms of financial assets that allow participation in the local economy, relating directly to social mobility, or the ability of individuals and families to move between social classes. Analysis of the recent 2007-2009 recession revealed a drop in employment for the disabled, from 5.4 million to 4.9 million; there was no significant change in the number of labor force participants without disabilities (Kaye, 2010). This study also found a 17.8 percent decline in employment for people with mobility disabilities between October 2008 and June 2010. More recently, the Bureau of Labor Statistics shows a decline in the employment rate by those with disabilities, and an increase in the number of people who dropped out of the labor force. Meanwhile the employment of the general

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population increased (Bureau of Labor Statistics, 2014). Kaye (2010) attributes the increase in unemployment and withdrawal from labor market to an increase in people collecting social security benefits.

The cost and effectiveness of both Social Security Disability Insurance (SSDI) and Supplemental Security Income (SSI) have been debated recently, as the number of people claiming benefits has increased in the last decade. The problems inherent in the programs are two-fold; anyone receiving government assistance must weigh the amount of benefits they receive against additional income that would cause them to lose SSI benefits. If they haven't worked long enough to sufficiently pay into social security, they may not qualify for SSDI benefits. The complexities of unemployment and the paucity of financial assistance put nearly a third of the disabled population of New York City under the poverty line (2010 Disability Status Report). An article in the New York Times last year described essentially a "Disability Trap" that keeps those with disabilities in a very low-income bracket (Turkewitz & Linderman, 2012). The structure of disability eligibility provides only a minimal safety net while severely limiting the incentive to be financially self-sufficient for fear of losing the safety net altogether.

The national employment rate for people with disabilities has fallen from 32 percent in 1981 to just 21 percent today, due in part to a failure dating back to 1974 by the Social Security Administration to structure the program in a way that motivates work. Information retrieved from the SSA's website highlights this disincentive:

Social Security's definition of disability is based on your inability to work.

Usually, if you are working and earning above a certain amount you are not considered "disabled" and, therefore, you cannot get any type of disability benefit.

("Social Security Online - Benefit Eligibility Screening Tool (BEST)," n.d.)

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Recipients must have little or no income, and can't have more than \$2,000 in a savings account. Supposed work incentives allow some income, but earnings that "exceed \$65 per month reduce the amount of benefit received... plus one-half of the amount over \$65." The monthly payment in New York for SSI for a single person is \$808/month ("Social Security Income," 2014). This amount is \$161 lower than the poverty line, a measure that some argue is insufficient for high-cost cities like New York (Rodriguez, 2012).

### **Time**

The notion of time is an important concept in both ecological and bioecological systems theories. The chronosystem includes internal and external events that have a formative impact on the developing person. The timing of historical events in the macrosystem can also determine development in the rest of the lifespan.

**Personal history.** The timing and nature of events shapes each individual's development. The age at which a person became disabled, and their changes in residential location were important themes that came out in the interviews.

***Age of Disability Onset.*** There was a range of the time since disability onset among the eight participants. The longest disability was 29 years, and the shortest was 4 years. The timing of disablement seemed to affect the life course of each person differently. Some factors included differences in educational attainment and work experience before disability. The timing of disability onset may have also impacted career trajectories and financial resources.

***Changes in residential location.*** For three of the participants, residential location didn't change, or only changed slightly because of their injury. For instance, one woman moved to a different apartment in the same building, two men moved back to their childhood homes at some point before or after becoming disabled, and another moved to an apartment that he lived in

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before becoming disabled. Decisions to change (or not change) location were influenced by family and the ability to make the apartments reasonably accessible. Several of the participants had plans to move out of New York City within the next few years, and one had plans to move to a nearby suburb within a year. These choices were also tied to an awareness of increasing disability, or a change in lifestyle since becoming disabled. Prentice described a long-term desire to move out of New York City:

Prentice: Somewhere south.

Jessica: In the south?

Prentice: Yeah. Every—I have a couple of friends there, that moved from here, from this very block to the [south]. Yeah, and they're like, 'Man, it's so slow, it's too slow,' but, slow motion is good for me sometimes. I mean, not all the time, probably want to pick it up—I won't be able to just pick up and go to Manhattan if I want to. Let's see, maybe I'm ready for slow motion because of my injury, because it slowed me down a lot. Before my injury, I was... ripping and running, going all over the place. I still do the things I loved to do before I was injured, I just do them differently now. Like football, for instance. I used to play, now I coach. I don't know, maybe it just changed my whole... my whole path, nature.

**History.** Natural experiments are empirical studies that seek to find correlations between changes and historical events. While some factors cannot be controlled for, as they might be in traditional experiments, having a well-defined group that is impacted by historical events may be enough to show relationships between events and outcomes within the group. In the case of people with mobility disabilities in a city-specific context, historical events of consequence would include federal and local policy changes that are meant to improve social conditions for

people with disabilities.

***Federal policies.*** The Americans with Disabilities Act was signed into law nearly 25 years ago, and has undoubtedly made a positive impact on improving accessibility for people with disabilities. The total impact is hard to measure, and is still incomplete in some of its goals, but its historic significance is important in the chronosystem for people with mobility disabilities. The recent amendment in 2008 has expanded the definition of disability and may bring even more awareness to invisible mobility disabilities.

There is also legislation waiting for a vote that would end policies limiting the amount of personal assets people with disabilities can accumulate. The Achieving a Better Life Experience (ABLE) Act would let people create tax-free savings accounts to use for health and wellness expenses, including assistive devices and transportation costs. The savings accrued would not disqualify individuals from receiving SSI or Medicaid.

***Lawsuits for accessibility improvements.*** In the past few years, there have been a number of lawsuits brought against the City of New York for failing to consider the rights of people with disabilities in areas such as accessible taxis, polling places, and inclusion in the city's emergency evacuation planning. A victory for Taxis for All Campaign will ensure that 50% of the Taxi and Limousine Commission's fleet is wheelchair accessible by 2020. A very recent filing (July 18, 2014) by the Center for the Independence of the Disabled New York (CIDNY) is taking on sidewalk quality in lower Manhattan. Time will tell how these developments change life trajectories for people with mobility disabilities.

## **Chapter 4: Questions for Policies and Future Research**

Through talking with people experiencing mobility disabilities in the city, it is clear that mobility disability impacts every area of life to some degree. While the participants in this small study have all found ways to adapt to their individual situations, many were living in less than ideal environments, working with limited transportation options, and more often than not, concerned about their financial resources. This brings up a number of questions about policies and practices impacting this community, and future research questions about how the *people*, *objects* and *symbols* (Bronfenbrenner & Morris, 2006) within the individual's ecological systems affect development when injury or progressive disease limits mobility. What research is needed to better understand the psychological impact of treatments and therapies, and user satisfaction with evolving assistive devices? How will these new devices change perceptions of mobility disability? How can we shape other important contexts for people with disabilities? What policies might help people with mobility disabilities reach their full potential?

### **Policy Questions**

In addition to federal policies that discourage people with disabilities from working, there are certain policy positions that disproportionately impact people with mobility disabilities. Many real-life outcomes have been discussed in the context section of the last chapter, especially in regards to the built environment. When access to public goods such as transportation and education are limited, participation in the economy is limited as well. Public transit networks, schools, housing and other critical infrastructure are a complex arrangement of government agencies that are subject to funding changes and oversight at different levels of government. Decisions about improving accessibility made by entities like the MTA, DOT and HUD are often based on avoiding ADA lawsuits and don't strive for universal standards that would do away

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with a need for special and separate accommodations. Creating just enough housing and transportation access to match the proportion of people with mobility disabilities is a flawed approach for a number of reasons. First, the idea that disabled people will somehow align with available accessible housing and transportation services is a strange notion; especially considering that mobility disability is often an acquired disability. Second, requiring new housing to fit with a proportion that was finalized before enough data was collected to show true prevalence ignores demographic changes. And third, failing to take existing housing stock with zero accessibility into account when requiring new accessible units means that the percentage needed will never be attained.

Just as state governments have the opportunity to offer additional supplemental security income, local governments have the opportunity to set stricter building standards. One problem is the missing voice of this constituency. Besides being disenfranchised by inaccessible polling places, transportation and accessibility issues keep people with mobility disabilities from using traditional means of protest to garner attention for their cause. George explained his frustration in mobilizing people to bring more awareness to the issues impacting their lives:

First of all, if the folks can't get around to deal with these issues and become that presence that's needed, then no one's ever going to learn about the issue. So, if you can't get around, you're not seen, and if you're not seen, you're not heard.

New York City agencies should learn more about issues that are most important to this silent minority, mandate accessibility improvements, and measure how these improvements affect the socioeconomic status and quality of life for people with mobility disabilities.

### **Future Research Directions**

Through asking questions about the somewhat mundane experiences of home, work, and

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transportation environments, a picture of daily life with a mobility disability emerged. Figuring out ways to measure and quantify these complex interactions is the next step. The theme of social interactions came up repeatedly, sometimes in response to questions about other people, but mostly in response to questions about the experience of being in public spaces. How can we better understand the impact of these interactions on the emotional health of people with disabilities and their loved ones? And, how can we better understand the ways in which the nondisabled population views people with physical disabilities, how they perceive their own likelihood of becoming disabled, and how those attitudes are changing over time?

**Longitudinal survey for the disabled and nondisabled population.** The Americans with Disabilities Act was passed in 1990, but generational differences in accessibility are still affecting different cohorts differently. Using a continuous survey for a longitudinal study could show gradual changes in the perception of accessibility in work, home and transportation environments, along with attitudes about physical disability. By repeating the same measure with a representative sample over a long period of time, and with the assumption that policy or economic changes happen between data collection times, subtle changes may become visible.

Questions would be framed in a way that both disabled and nondisabled people could answer, but they would be centered on the experience of people with mobility disabilities. For example, questions about transportation accessibility would use a Likert scale that enables people to provide the degree to which they agree with statements such as, “I believe that wheelchair users and people with other mobility disabilities can use public transportation with ease.” Or, “I believe that people with physical disabilities can access a majority of businesses in my neighborhood.” Or, “Physical disabilities prevent people from achieving the same goals as people without disabilities.” Or, “Accessibility in buildings already impacts my life or will

impact it in the future.” Differences in responses between the nondisabled and disabled participants reveal which areas may be lacking awareness, or how pervasive ableist attitudes are within each group. At the same time, looking at the responses from people of different ages may reveal if people become more aware of accessibility issues or less as they get older, and repeated measures may reveal if and how these perceptions are changing over time.

**Qualitative study with interviews and observations.** With more time, experience from the pilot study, and further theoretical development, a second qualitative study can dig deeper into the importance of context and processes of change discussed here. Observations were originally intended to be part of the pilot study, but building trust and developing relationships with participants was challenging in the few months allotted for the study. After refining recruiting methods, and finding more allies to help with the process, there is a good chance of success for a larger-scale study that asks these questions more systematically. More emphasis on finding working participants, and participants with children will also be important to answering questions that are outlined below.

### **Disability Impacts on Family and Work**

How do work-family topics outlined in Chapter 2 relate to people with mobility disabilities? There is some research on physical disability and family cohesion (Franklin, 1977, Alexander, Hwang, & Sipski, 2002), but very limited research on disability, work and family when the research relates to a disabled parent rather than a child (Clarke & McKay, 2008). Drawing upon work-life literature, interviews of disabled people and their partners may reveal patterns of division of labor, and work-family conflict or enrichment within the group.

**Children’s development and relationship with disabled parents.** I did not seek permission to interview or observe children in this initial study, but the parental role was quite

important to those that had children living at home or elsewhere. In searching for existing qualitative research at that involves parents with disabilities, I came across only one recent study from Toronto of parents with spinal cord injuries (Kaiser, Reid, & Boschen, 2012). The authors found that the parents faced all of the issues outlined in previous chapters, and in addition, social stigma and criticism of their ability to fully care for their children. Approaching research into childhood development should attempt to find positive influences of having a disabled parent on childhood development in addition to understanding stigma and other negative aspects of the

**Role of personal assistant in relation to individuals, families and coworkers.** Another area lacking research is the role of personal assistants and their relationship to families or work colleagues. In cases where around-the-clock care is needed, several people make take up this role. The compatibility of the personal assistant and the person they are taking care of is one area of investigation, but the more removed relationships between the personal assistants and other people within the disabled person's ecosystems is also worth examining.

## Chapter 5: Conclusion

In expanding on Elder's life course theory, Bronfenbrenner and Morris (2006) add an important principle to his observations about history's role in the individual's development;

“Simply stated, the fifth principle asserts that changes over time in the four defining properties of the bioecological model are not only products but also *producers* of historical change” (p. 822).

The voices of people with mobility disabilities and their advocates are perhaps the most important driver for historical change, but as George mentioned, their voices are sometimes not loud enough. The implications of not being heard will continue to impact future generations, and current generations in the future, as inaccessible spaces continue to be built. Awareness of the issues faced by this community is far from universal, and many nondisabled people I've spoken to throughout the course of this research project were unaware of many critical issues in New York City. Alexandra relayed her experience in trying to increase awareness in her own neighborhood by interviewing with a local blog about inaccessible businesses. They contacted one such business owner:

We have a shop owner, and when we were doing this article thing, where he said, 'Well, we've never had a complaint before,' and we said, 'Well, of course you haven't, no one can get into your store to complain!' It's just that silly thing, of course, but how do you open people's eyes to it?

Policies and research can go further to understand how to fix these barriers, but much of the battle still remains in raising awareness of how inaccessible places affect not just physical mobility, but social mobility as well. Measuring the impacts of policy changes is also crucial in order to understand how changes are making a difference.

**Measuring economic outcomes.** Often, policies have unintended consequences, and changes to certain laws affect other policy areas. Looking at employment numbers since the ADA was passed shows that employment rates have actually gotten worse (Nazarov & Lee, 2012), though the reasons for this are complex. For instance, there is some evidence that welfare reform in the 1990s has led to a major increase in the number of people collecting disability (Joffe-Walt, 2013). What was intended as a way to encourage states to take more responsibility for their own welfare rolls has ended up shifting the burden back to the federal government, putting the entire social security system at risk. Measures meant to reduce fraud and abuse have actually kept people permanently out of the workforce and reliant on government assistance. Understanding economic outcomes on an individual level is an important area for longitudinal research.

**Measuring well-being outcomes.** Defining well-being or quality of life is a challenge, but it is a worthwhile goal to understand how this construct changes over time. In addition to objective measures that can predict well-being, research should examine longitudinal changes in satisfaction with the many environments that make up a person's life. Continued exploration of subjective well-being is important for advancing systems theories and understanding the true impact of context at different levels throughout the ecosystem.

### **An Ecological, Life-Span Approach to Accessibility**

The argument for universal design strongly supports the notion of designing for a lifetime, but hyperbole about costs has slowed progress in accessibility improvements. Neoliberal policies have taken over the transportation and planning policies of major cities, yet governments fail to see that exclusionary practices cost more in the long-term. Neglecting to design for people of all abilities and ages puts those impacted by design shortcomings at an unjust disadvantage.

**Mobility of parents and young children.** The European Rail Vehicle Accessibility Regulations of 2008 changed the definition of *persons with reduced mobility* to include people with disabilities as well as others that may experience reduced mobility, such as pregnant women, and people travelling with small children. This inclusive definition expands direct benefits to a larger portion of the overall population, and draws attention to other nondisabled segments of the population that have limited mobility.

**Mobility of an aging population.** The potential for broader support for universal design may come from a rapidly growing segment of the population. The 65+ population in New York City is set to exceed a million residents before 2020, and will continue to rise in the decades to follow (New York City Population Projections by Age/Sex & Borough 2000–2030). Some say the nation’s housing isn’t ready for the looming demographic change, but the realities of an aging population will force many to reconsider designing for both the elderly and disabled despite those who don’t want to face the uncomfortable truth that we will all eventually get older (Badger, 2012). Support for the elderly is crucial to ensure continued social integration and mobility impacts the tendency to be homebound after reaching a certain age (Stowell-Ritter, Bridges, & Sims, 2006). The Mayor’s office and other city organizations are beginning to pay attention to the needs of the elderly, but most measures don’t go far enough or ask tough questions about housing and transportation needs.

100% of the population benefits from accessibility improvements, at least a small percentage of the time. Making universal access a personal issue with direct connections to “our future selves” (Hanson, 2001) raises the stakes for the entire population, and is key to a broader social movement that will foster permanent change.

### **New York City, a Global City**

Global cities are those that Sassen (1991, p.19) describes as having “vast concentrations of hypermobile dematerialized financial instruments and the enormous concentrations of material and place-bound resources that it takes to have the former circulating around the globe in a second.” New York has been at the top of the A.T. Kearney Global Cities Index since its creation in 2008. The index measures factors in five dimensions: business activity, human capital, information exchange, cultural experience, and political engagement, and ranks large cities based on their relative influence in the world (Amburn, 2008).

While other global cities like Tokyo are providing greater accessibility to public transportation and public places, New York appears to be stubbornly stuck in a time before wheelchair accessibility was deemed important. Resources and guidelines for universal design abound, but developers continue to build inaccessible buildings. Advocacy groups are fighting to ensure basic rights for disabled people, but this fight is taking place in the courtroom. Actual cost estimates are rarely cited when public entities resist universal design principles, so it’s difficult to know how these costs compare to the legal costs incurred fighting accessibility lawsuits. No matter how far behind New York City may seem in comparison to other developed countries, the situation is far worse in the developing world.

The recent election of a mayor backed by the liberal Working Families Party offers some hope that these issues will be heard and prioritized in the near future. If New York City were to go above and beyond federal and state guidelines to improve inclusion for people with mobility disabilities, this message would set a strong example for the nation and the world.

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